The lived experiences and embodiment of asthma and sports and exercise in the South Asian population: An interpretative phenomenological analysis

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Conference Presentations

Yusuf, Z. "An insight into the lives of South Asian people with asthma and their sporting experiences" at the De Montfort University Research Student Poster Competition. De Montfort University, Leicester, 5th April 2017.

Yusuf, Z. "Working out asthma: An investigation of the experiences and embodiment of asthma and sports and exercise in the adult South Asian population" at the Midlands Health Psychology Annual Conference, Kettering, 24th May 2018.

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Abstract

Individuals of South Asian origin with asthma in the UK are more likely to experience excess morbidity and increased hospitalisation rates compared to their White British counterparts. South Asian groups also have lower levels of active participation in sport and/or exercise and are less likely to maintain an exercise regime. There is limited research investigating the experiences of asthma and sport and/or exercise specific to the UK-resident South Asian population and therefore this thesis was designed to explore this.

This study used a qualitative, interpretive, phenomenologically-inspired approach and employed a single method design. In-depth semi-structured interviews were conducted with 14 participants (12 female, 2 male) of Indian, Pakistani, Bangladeshi and Sri Lankan ethnic origin, who had experience of asthma and sport and/or exercise. Their accounts were analysed using interpretative phenomenological analysis (IPA), informed by a symbolic interactionist (SI) perspective. Central to the findings in this study was the presentation of the asthma self in an everyday and sporting context. Goffman's (1959; 1963) conceptual analysis of self-presentation and stigma, together with Leder's (1990) phenomenologically-inspired insights on the 'absent' body and 'dys-appearing' body, with Zeiler's (2010) phenomenologically-inspired notion of the 'eu-static' body, were employed to understand these phenomena.

Seven superordinate themes were formed from the participants' data: negotiating the asthmatic identity; how they manage their medication; the impact of culture and how it affects treatment behaviour; integrating sport and/or exercise into their everyday lives; reasons for non-engagement in sport and/or exercise; stigma; and lastly the participants' relationships with healthcare professionals.

Recommendations for healthcare practice and policy include considering cultural stigma and ascertaining exactly which UK-resident South Asian communities require a better awareness of asthma. Patient sensitivity should be considered, as well as the stigmatising effects of asthma on sporting and/or exercising experiences. Sporting bodies need to acknowledge the role of South Asian cultural and gender differences when aiming to improve sport and/or exercise participation. Furthermore, healthcare professionals need to consider whether their patients perceive themselves to be 'asthmatic' and understand how this might affect medication taking behaviour, as well as being culturally responsive and discussing the use of non-pharmacological treatments in a non-judgemental manner. Finally, it is imperative that the patient and HCP aim to achieve a therapeutic relationship where they share similar notions about treatment objectives.

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Glossary of Terms

Asthma control	Referred to as the prevention of symptoms and the extent to which symptoms of asthma are reduced by treatment, which can vary (Dozier, Aligne & Schlabach, 2006; Reddel et al., 2009).
Asthma exacerbation	Defined as the progressive worsening of asthma symptoms, and which usually require a change of treatment (Fuhlbrigge et al., 2012).
Asthma severity	This is the intrinsic intensity of the condition and dictates the treatment process (National Asthma Education & Prevention Program 2007). The severity of one's asthma is assessed during treatment (Taylor et al., 2008).
Beclomethasone dipropionate	This is a steroid medication and is used as a preventer inhaler. In the UK, it is sold under the brand names Clenil Modulite® and Qvar®. It is available as an aerosol and dry powder inhaler and is used for the long-term treatment of asthma (Joint Formulary Committee, British National Formulary (BNF), online, 2019).
Budesonide with formoterol	This is a combination of steroid and beta 2 agonist medication used in the treatment of asthma and chronic obstructive pulmonary disease (COPD) and is sold under the brand name Symbicort and Fostair (Joint Formulary Committee, BNF, online, 2019).

Chronic illness	Defined as a long-term illness which does not have a medical cure currently available. There are four main types; cardiovascular diseases (such as, heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes (World Health Organisation (WHO), 2016).
Co-morbidity	The presence of one or more additional conditions, which co-occur(s) with a primary condition (Valderas et al., 2009).
Exercise-induced asthma (EIA) or exercise-induced bronchoconstriction (EIB)	Relates to airflow obstruction that occurs because of exercise in susceptible individuals. It was previously termed as exercise-induced asthma, however, this term incorrectly suggested that exercise can cause asthma (Cooper, 2008).
HIIT training and/or workout	High intensity interval training (HIIT) or high intensity intermittent exercise (HIIE) is a form of cardiovascular interval training (Laursen & Jenkins, 2002). It involves alternating between short, intense periods of aerobic exercise with less intense recovery phases. The success of participation during HIIT and/or HIIE sessions is dependent on a person's current fitness level (Laursen & Jenkins, 2002). Thus, the duration and intensity of a HIIT and/or HIIE session varies between individuals (Laursen & Jenkins, 2002).
Late-onset asthma	The development of asthma in later life, now more commonly referred to as adult-onset asthma Asthma UK, 2018).

Medication adherence	This is defined by WHO (online, 2018) as *"…the degree to which the person's behaviour corresponds with the agreed recommendations from a healthcare provider*." This suggests that the patient and healthcare professional work together to improve the patient's health by incorporating both the patient's and healthcare professional's opinions and the patient's lifestyle behaviours, beliefs and preferences for care (Jimmy & Jose, 2011).
Medication compliance	This is the extent to which a patient's behaviour corresponds with their healthcare professional's advice (Horne, 2006). Compliance implies that the patient is submissive to their healthcare professional's authority.
Montelukast	This is used in the treatment of asthma as an add-on therapy. It is for patients with mild to moderate asthma, who are inadequately controlled on inhaled corticosteroids. It is used when 'as-needed' short-acting beta agonist treatment provides inadequate control (Joint Formulary Committee, BNF, online, 2019).
Nebuliser	This is a machine which assists susceptible individuals to breathe in the medicine using a mask or mouthpiece (NHS, 2018b).
Preventer inhalers or steroid inhalers	Steroid inhalers, also called corticosteroid inhalers, are prescribed for susceptible individuals for regular use to prevent symptoms of asthma developing (NHS, 2017). The common drug in these inhalers is steroids and work by reducing inflammation in the airways, which can help reduce symptoms (NHS,

	2017). They are often called ‘preventer inhalers’ because they are used to help prevent symptoms (NHS, 2017). Common types of preventer inhalers include steroids, such as, beclomethasone, budesonide, fluticasone and mometasone (NHS, 2017).
Prednisolone	This is a type of medicine, known as a corticosteroid or steroid. It is used to help reduce inflammation (NHS, 2019). In the UK, prednisolone is a prescription only medicine (POM). It is provided in the form of tablets which are water soluble (NHS, 2019). It can also be given by injection; however, this can only be conducted if the patient has been admitted to hospital (NHS, 2019).
Reliever inhaler or salbutamol inhaler	This is used to relieve symptoms of asthma, such as coughing, wheezing and shortness of breath. It works by relaxing the muscles of the airways when it is inhaled, which makes it easier to breathe (NHS, 2018a). Salbutamol inhalers are normally blue (NHS, 2018a). It is available in different formulations, including tablet, syrup and injection (NHS, 2018a). Additionally, it can be given through a nebuliser, but this is normally only if a susceptible individual has severe asthma (NHS, 2018a). Salbutamol is only available on prescription (NHS, 2018a) and a variety of branded inhalers are available, such as, Salamol Easi-Breathe inhaler and Ventolin.
Symptom perception	This is defined as the patient's conscious awareness of a physiological problem (Banzett et al., 2000), and the ability to detect physical symptoms of asthma, including breathlessness, wheeziness, and chest tightness (Lane, 2006).

Abbreviations

AAAAI	American Academy of Allergy, Asthma and Immunology
ABPI	Association of the British Pharmaceutical Industry
BLF	British Lung Foundation
BTS	British Thoracic Society
BSA	British Sociological Association
CPPE	Centre for Pharmacy Postgraduate Education
EIA	Exercise-induced asthma
EIB	Exercise-induced bronchoconstriction
GINA	Global Initiative for Asthma
GP	General practitioner
HCP	Healthcare professional and/or practitioner
ICS	Inhaled corticosteroids
LABA	Long-acting beta agonists
NHBLI	National Heart, Lung and Blood Institute
NHS	National Health Service
NIoH	National Institutes of Health
NRAD	National Review of Asthma Deaths
ONS	Office for National Statistics
POM	Prescription only medicine
SABA	Short-acting beta agonists
SIGN	Scottish Intercollegiate Guidelines Network

UK	United Kingdom
US	United States
WHO	World Health Organisation

Chapter One: Introduction

1.1 Introduction

Asthma is one of the most common chronic illnesses in the world (WHO, online, 2014) and affects approximately 334 million people of all ages and ethnic groups worldwide (Pickles et al., 2018). The United Kingdom (UK)[1] has one of the highest rates in Europe, with approximately 4.3 million UK-resident adults diagnosed with some form of asthma (Asthma UK, 2018a). There are several different types of asthma (Asthma UK, 2016). Various terms are used to describe the different types of asthma (Asthma UK, 2016). This is because people with asthma experience the condition differently (Asthma UK, 2016). This makes it difficult to place asthma into exact categories, although asthma is normally defined by one or more of the types below (see Table 1 overleaf, p. 18) (Asthma UK, 2016). As a group, people with asthma are less likely to be active and participate in intense or vigorous exercises such as cycling and sprinting, than those without asthma (Weiner, McDonough & Allen, 2007; Westermann et al., 2008). According to Del Giacco (2015), people with asthma have a unique response to exercise and sport. Although participation in exercise and sport can provoke symptoms such as breathlessness and chest tightness in a susceptible individual, regular participation in exercise and sport can benefit people with asthma, including reducing the risk of further illness, and improving pulmonary function (Del Giacco, 2015).

Asthma is a serious illness and complications arising from the condition can result in death (Asthma UK, 2016). Supported by Asthma UK, the national review of asthma deaths report (NRAD) (Royal College of Physicians, 2014) revealed that despite the advancement of modern drugs and various pharmaceutical techniques and guidelines, factors such as poor monitoring of basic treatment by both healthcare professionals (HCPs) and patients were identified in over 60 per cent of asthma deaths during 2012-2013. The key findings from the NRAD report suggested that both the patient and HCP played a role in this (Royal College of Physicians, 2014). According to the NRAD, 46 per cent of deaths were attributable to patients not following the appropriate guidelines, possibly underplaying the seriousness of asthma (Royal College of Physicians, 2014). There was also evidence indicating that HCPs were excessively prescribing reliever prescriptions without advising patients to take inhaled steroids (Royal College of Physicians, 2014), as well as a failure to provide personalised asthma action plans to some patients (Asthma UK, 2014; Royal College of Physicians, 2014). The most recent data available showed that more than 1,400 people died from asthma in 2018; an 8% increase compared to 2017 (Asthma UK, 2018c).

[1] UK statistics for Asthma UK include England, Wales, Scotland and Northern Ireland (Asthma UK, 2018a).

1.2. Asthma in the UK South Asian population

Preliminary research (see Gilthrope et al., 1998; Griffiths et al., 2001; Netuveli et al., 2005) reported that individuals of South Asian origin with asthma in the UK are more likely to experience excess morbidity and three times higher hospitalisation rates, than for those of White British origin. In Birmingham (Ayres, 1986) and Blackburn (Myers & Ormerod, 1992; Ormerod, 1995), two heavily populated areas for people of South Asian origin, the risk of admission was more than double for South Asians than that for White British adults with asthma, however, this evidence is more than 30 years old. More recent evidence (The Tower Hamlets Joint Strategic Needs Assessment report, 2015; Sheikh et al., 2016) has demonstrated that South Asians remain at an increased risk of hospitalisation due to asthma. The 2015 Tower Hamlets Joint Strategic Needs Assessment report, in particular, reported that there has been little change in the rates of hospitalisation for South Asians, since Gilthorpe et al.'s (1998) and Netuveli et al.'s (2005) investigations between 10-20 years ago, suggesting that evidence from 10-20 years ago remains relevant today. The rates vary between locations in the UK. For example, the Tower Hamlets Joint Strategic Needs Assessment report (2015) was based in London and Sheikh et al.'s (2016) research investigated hospitalisation rates for Scotland-resident South Asians with asthma. Sheikh et al.'s (2016) study indicated that there are also ethnic variations for asthma-related hospitalisations within the South Asian population, specifically for adults of Indian and Pakistani origin. With a higher risk of hospital admission, adults from South Asian groups are at an increased risk of poorer outcomes (Sheikh & Griffiths, 2005). Additional work is required to understand why these groups are at an increased risk of hospital admission (Hull et al., 2016).

Types of asthma	Description
Occupational asthma	Asthma that is caused by the workplace.
Difficult to control/ or severe asthma	• Characterised by breathing difficulties almost all of the time. • Often experience asthma attacks. • Those with severe asthma fall into two groups: 1. Symptoms that can be treated 2. Symptoms that do not respond to treatment • Severe asthma was previously described as 'brittle' and 'refractory' asthma. • There are also different types of severe asthma, which usually affects adults.
Adult onset asthma	Adult onset asthma or late onset asthma refers to people who are diagnosed with asthma when they are adults.
Childhood asthma	Asthma diagnosed in childhood.
Seasonal asthma	Seasonal asthma relates to people who only experience symptoms during specific times of the year, for example, during the cold weather.

Table 1. Different types of asthma (adapted from Asthma UK, online, 2016).

1.3 Asthma, sport and exercise in the South Asian population

Research examining the relationship between asthma and sport and exercise behaviour in the South Asian adult population is limited and has shown varying results. Existing UK-based research (e.g., Lawton et al., 2006) has focused on the motivations and barriers towards sport and exercise in South Asian groups with a range of co-morbid conditions, such as asthma, diabetes, and cardiovascular disease. Lawton et al. (2006) conducted a qualitative examination of Indian and Pakistani South Asian adults living in the UK, who had been diagnosed with Type 2 diabetes. Some of their respondents had also been diagnosed with asthma and claimed that symptoms such as breathlessness made it difficult for them to exercise (Lawton et al., 2006). The role of asthma, however, was not the central focus in Lawton et al.'s (2006) study, and there was no further information provided by Lawton et al. (2006) about the respondents' relationship between asthma and sports and exercise (see section 2.3 for a further critique).

Previous research (see Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et al., 2000; SportScotland, 2001; Carroll, Ali & Azam, 2002; Rishbeth, 2004; Lawton et al., 2006; Netto, McCloughan & Bhatnagar, 2006; Openspace, 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008; Jepson et al., 2008; Keval, 2009; Ahmad, 2011; Jepson et al., 2012; King & Little, 2017) has focused on the motivations and barriers to sport and exercise participation in the UK-resident South Asian population because they are less likely to participate in sport and exercise than other minority and majority groups (Jepson et al., 2012). For example, when Williams et al. (2011) compared levels of active participation between UK-resident South Asian adults and White British adults, the results indicated that South Asian adults were less likely to begin or maintain an exercise regime, when compared to their White counterparts. There is, therefore, an interest towards establishing the motivations and barriers of sport and exercise, in order to improve active participation levels in the South Asian population (Jepson et al., 2012). While these studies have provided valuable insights, they did not focus solely on the relationship between asthma and sport and exercise in this population or explore how sport and exercise is managed by UK-resident South Asian adults with asthma. Thus, evidence about the role of sport and exercise behaviour for UK-resident South Asian adults with asthma remains scarce.

1.4 Thesis statement

The purpose of this thesis was to explore the phenomena of UK-resident South Asian adults with asthma and their sport and/or exercise experiences. It was important to ascertain how the participants in the present study managed asthma, since the UK-resident South Asian population are currently at higher risk of hospital admission (Gilthrope et al., 1998; Griffiths et al., 2001; Netuveli et al., 2005; The Tower Hamlets Joint Strategic Needs Assessment report, 2015; Sheikh et al., 2016), owing to potentially fatal consequences of poor asthma self-management (Sheikh & Griffiths, 2005; The Tower Hamlets Joint Strategic Needs Assessment report, 2015; Sheikh et al., 2016). Additionally, it was important to understand their sport and exercise behaviour, given the low rates of participation by UK-resident South Asians (Jepson et al., 2008). These issues are discussed in further detail in the following chapter (see Chapter Two). The limited evidence on this topic leads to the consideration that UK-resident adult South Asians are under-represented in this area, and thus, the current research added to this gap in the literature. This thesis therefore aimed to further understanding about UK-resident adult South Asian populations with asthma and their sporting and exercise experiences.

The current study explored the phenomena of UK-resident South Asian adults with asthma and their sporting and/or exercise practices and identified factors which facilitate or limit their use of medication. It did so by drawing upon in-depth interviews with UK-resident South Asian adults who have been diagnosed with asthma, and who are, or have been, involved in sport and/or exercise. By placing UK-resident South Asian adults' voices at the fore, this study considered the role of South Asian culture and helped to capture cultural differences (see Chapter Five for a detailed discussion). Limited attention has been paid to how UK-resident South Asian adults experience asthma, their exercise and/ or sporting practices and how they negotiate their cultural identity as UK-resident South Asians. This thesis filled this gap by considering the role of South Asian culture, and the ways in which it shaped and influenced individuals' attitudes and behaviours towards asthma management and sporting and/or exercising behaviour. The current study offered a unique opportunity to enhance the understanding of South Asian adults' experiences of asthma and sport and/or exercise and the role of South Asian culture in a UK-resident population.

This thesis was positioned at the intersection between psychology, sociology, healthcare practice, and sporting disciplines; it examined the importance and impact of cultural diversity by

exploring participants' critical accounts to inform medical practices. There has been a major focus on UK-resident South Asians experiences of asthma (Griffths et al., 2001; Hussein & Partridge, 2002; Bird et al., 2011; Lakhanpaul et al., 2015; Griffiths et al., 2016; Lakhanpaul et al., 2017; Ahmed et al., 2018; Lakhanpaul et al., 2019) within psychology, sociology and nursing and medical disciplines. The existing studies on the experiences of asthma have focused on medication behaviour (Griffths et al., 2001; Hussein & Partridge, 2002), childhood populations with asthma (Bird et al., 2011; Lakhanpaul et al., 2014; Lakhanpaul et al., 2017; Lakhanpaul et al., 2019), and the multifaceted nature of culturally-specific self-management interventions to improve asthma self-management behaviours (Griffiths et al., 2016; Ahmed et al., 2018). The current study added new insights into the experiences of South Asian adults with asthma and, more specifically, the role of the cultural and sporting identity in the context of asthma.

1.5 Research aims

This research offered an approach that values South Asian peoples' subjective experiences and insights of sport and exercise and addressed how they create meaning in relation to the lived experience of asthma, sport and/or exercise. The main research question was: How do UK-resident South Asian adults experience asthma, sport and/or exercise. This was considered by addressing the following research objectives:

- What are the experiences of UK-resident South Asian adults with asthma, who have, or are currently engaging in sport and exercise, who were born in the UK or migrated to the UK at an early age?
- How do UK-resident South Asian adults manage their asthma, and how is asthma treated?
- What roles do sport and exercise play for UK-resident South Asian adults with asthma, and how is sport and/or exercise managed?
- What are the implications of these phenomena for healthcare policy and practice in the UK?

This introductory chapter briefly describes the anatomy, physiology and biology of the respiratory system and the mechanisms of breathing. The pathophysiology of asthma and the triggers and symptoms of asthma are discussed, before a description of the treatment of asthma. The chapter concludes with an overview of the thesis structure.

1.6 The respiratory system

1.6.1 Anatomy, physiology and biology

The respiratory system is specifically designed to provide oxygen to the blood and remove carbon dioxide (Saladin, 2014). The main organs include the nose, larynx, bronchi, lungs, airways, trachea (windpipe) and pharynx (throat) (Saladin, 2014). Approximately six to ten litres of air are inhaled in and out of the lungs per minute and 0.3 litres of oxygen are transported from the alveoli (air sacs) to the blood per minute (National Heart, Lung & Blood Institute (NHLBI), online, 2015). The number of breaths taken per minute should be 10-12 during normal breathing and the volume of each breath should be around 500ml (NHLBI, online, 2015). This provides a healthy volume of 5-6 litres of air per minute (NHLBI, online, 2015).

1.6.2 Mechanisms of breathing

1.6.2.1 Breathing in (Inhalation)

Breathing is usually an involuntary (unconscious) act (Ward, Ward & Leach, 2010). The respiratory muscles, specifically the diaphragm and the intercostal, neck and abdominal muscles are used to achieve inhalation and exhalation (Ward et al., 2010). Inhalation is an active process and is when the diaphragm contracts in a downward direction, increasing the volume of the chest cavity where the lungs expand. The intercostal muscles also help widen the chest cavity (Ward et al., 2010). When a person inhales, the intercostal muscles contract, pulling the ribcage in both inward and outward directions (Ward et al., 2010; NHLBI, 2015).

As the lungs expand, air is drawn in from the nose or mouth due to the change in pressure (Saladin, 2008). The oxygenated air travels down the trachea and enters either one of the two bronchi leading to each lung (Saladin, 2008). The oxygen from the air then passes through the thin walls of the alveoli to the surrounding capillaries (blood vessels) (Saladin, 2008). The alveoli are the location for oxygen exchange, the passage of CO_2 to and from the bloodstream and for pulmonary circulation (Saladin, 2008). A protein called haemoglobin carries the oxygen throughout the body (Saladin, 2008). At the same time, carbon dioxide that has been dissolved in the blood is removed from the capillaries back into the air sacs, ready to breathe out (Saladin, 2008; British Lung Foundation (BLF), online, 2019). The gas travels from the right side of the heart into the bloodstream via the pulmonary artery (see Figure 1 for a detailed image of this process, p. 23)

(Derenne, Macklem & Roussos, 1978; De Troyer, Kirkwood & Wilson, 2005).

1.6.2.2 Breathing out (Exhalation)

Exhalation is a passive process and happens when the muscles relax, and the volume of the chest cavity decreases (NHLBI, 2015). It is when the pressure increases above air pressure outside of the lungs, meaning air leaves from higher pressure to enter lower pressure and equalises the pressure inside and outside of the lungs (NHLBI, 2015). The image below (see Figure 1, p. 23) demonstrates the anatomy of the respiratory system. Figure 2 (see p. 24) illustrates when a person exhales, their diaphragm eases and moves in an upward direction into the chest cavity and the intercostal muscles help reduce the space in the chest cavity (NHLBI, 2015). As the space in the chest cavity reduces, air containing carbon dioxide is removed from the lungs and windpipe first, and then from the nose and the mouth (Ward, Ward & Leach, 2010).

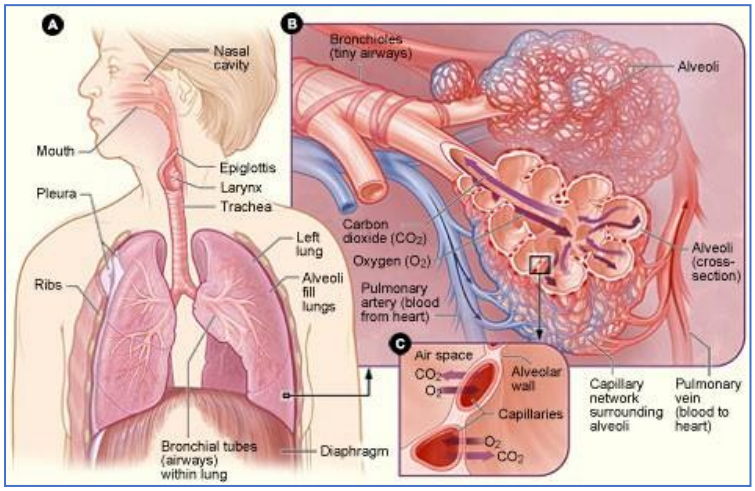

Figure 1. The anatomy of the respiratory system (NHLBI, online, 2015).

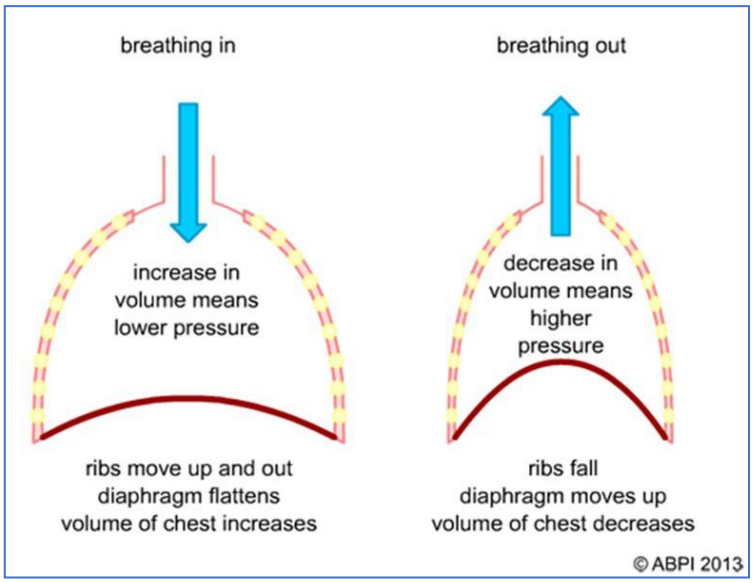

Figure 2. The inhalation and exhalation process of the respiratory system (The Association of the British Pharmaceutical Industry (ABPI), online, 2013).

1.7 Asthma

Asthma affects a person's breathing process because it causes inflammation of the airways, reducing airflow (Doeing & Solway, 2013). It is most commonly categorised by episodes of wheezing, tightness of the chest, coughing, and breathlessness (NHLBI, 2015). It is caused by an inflammation in the airways or bronchi, which are the small tubes responsible for moving air in and out of the lungs (NHLBI, 2015). Inflammation from the nose to the lung occurs, causing inflammation of the bronchi (NHLBI, 2015). This prompts less air to travel to the lung tissue, since there is an expiratory wheeze because of the active process of trying to expel air through a narrower bronchial tube (see Figure 3 below, p. 25) (NHLBI, 2015).

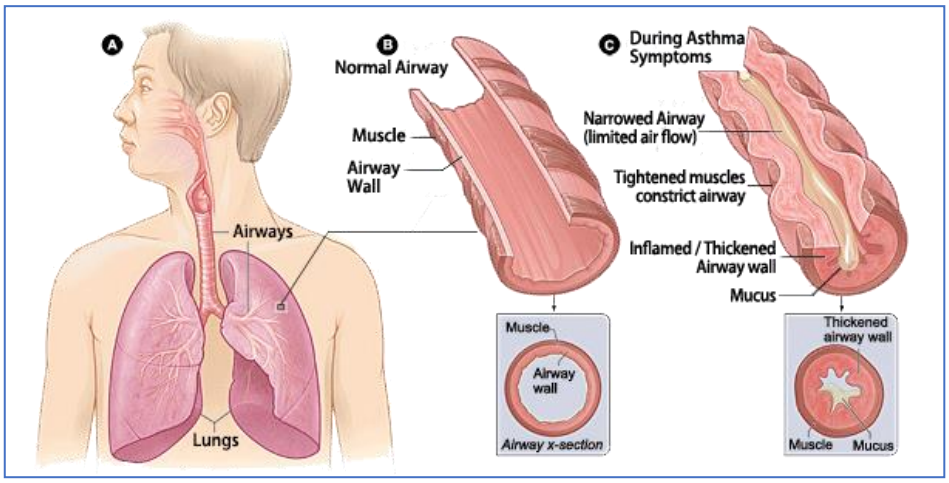

Figure 3. The airways. Figure A displays where the lungs and airways are located in the body. Figure B illustrates the cross-section of a normal airway, and Figure C demonstrates the cross-section of an airway when an individual experiences symptoms of asthma (NHLBI, online, 2015).

1.7.1 Triggers of asthma

Exposure to respiratory triggers such as upper respiratory infections (colds or sinus infections), environmental allergens (pollen, dust, animal dander, moulds, fungi, polluted air), powerful odours such as incense or cologne, cold air, emotional stress and hyperventilation (laughing, crying) alter the sensitivity and hyper-responsiveness of the airways in a susceptible individual (NHLBI, 2015).

Recurrent exposure to respiratory triggers can cause permanent narrowing of the airways and scarring (The American Academy of Allergy, Asthma & Immunology (AAAAI), 2018). Table 2 (p. 26) displays some of the common triggers of asthma, according to the NHLBI (2015) and the AAAAI (2018).

• Allergens from dust, animal fur, cockroaches, mould, and pollens from trees, grasses, and flowers, strong odours, or fumes.	• Irritants including cigarette smoke, air pollution, chemicals or dust in the workplace, compounds in home furnishing products, and sprays (such as hairspray)
• Medicines such as aspirin or other non-steroidal anti-inflammatory drugs such as, ibuprofen	• Sulphites in foods and drinks
• Exposure to weather changes, including cold or dry air conditions	• Physical activity, including sport and exercise
• Acid reflux, with or without heartburn.	• Emotional anxiety and stress
• Viral and bacterial infections	

Table 2. Common triggers of asthma, adapted from NHLBI (online, 2015) and AAAAI (online, 2018).

1.7.2 Symptoms of asthma

Symptoms of asthma occur when there is exposure to irritants or substances that trigger allergies, irritating the airways, leading to inflammation and constricting the flow of air making it difficult to breathe (Brannan & Lougheed, 2012; Asthma UK, 2018b), although underlying inflammation is common (Asthma UK, 2018b). When the inflammation is worsened, it leads to an asthma attack and/or exacerbation, where the airways become much narrower as a result of increased inflammation of the airways and the overproduction of mucus secretion (Brannan & Lougheed, 2012). This further obstructs the flow of air into the lungs, making it extremely difficult to breathe (Brannan & Lougheed, 2012). Attacks can be acute or severe dependent on the level of inflammation and the level of irritation leading to a spasm (Brannan & Lougheed, 2012).

The symptoms and triggers of asthma, as well as the frequency of asthma can vary between individuals and from episode to episode (Aaron et al., 2017). In addition, susceptible individuals are likely to experience relapses of asthma throughout their lifespan (Asthma UK, 2018b). Institutional definitions of asthma are becoming increasingly inclusive to better help define healthcare policies and improve asthma management (Bousquet et al., 2007). This is important

because some healthcare information for patients characterises the different levels of severity of asthma based on the frequency of the patients' individual symptoms (see Figure 4, for Colice's (2004) categories of severity). This helps the patient understand their level of severity and make a judgement based on their own experiences (Colice, 2004).

Types of asthma:

Intermittent = symptoms occur either twice a week or less

Mild = Symptoms occur more than twice a week but less than once a day

Moderate = Symptoms occur daily

Severe = Symptoms occur daily and often (for e.g., disrupt sleep)

Exercise-induced = Symptoms triggered by exercise

Figure 4. Categories of asthma severity, as defined by Colice (2004).

People with asthma must learn how to accommodate their condition (Pinnock, 2015). They may need to learn how to use their medications, remember to take their medication regularly, keep their inhalers on their persons, re-stock their inhalers, learn about and avoid triggers where possible, and cope with the variable nature of asthma and how this might impact their lifestyle (Pinnock, 2015).

Most importantly, they have to learn how to recognise when their condition begins to deteriorate, decide which medications to use, and when to seek professional help (Pinnock, 2015).

1.8 Asthma management and control

A medical cure for asthma does not currently exist and asthma is managed best by controlling and treating the symptoms (British Thoracic Society (BTS), 2016; Scottish Intercollegiate Guidelines Network (SIGN), 2016; NHS, 2018a). The BTS (2016) and SIGN (2016) guidelines endorse a stepwise treatment approach (see Figure 5, p. 28, for the BTS and SIGN (2016) stepwise approach). As discussed in section 1.6.2, asthma is a condition with variable symptoms, and as a result, there is a variable requirement for medication (Morrison, 2016). This is illustrated visually in the stepwise management approach (see Figure 5, p. 28), which shows an arrow going either upwards or downwards. In order to achieve appropriate control and effective

management of symptoms, a person's treatment approach changes according to whether their condition worsens over time or improves (Morrison, 2016). This is called 'stepping up' or 'stepping down' (Morrison, 2016). This approach can steadily enhance respiratory function and help patients achieve symptomatic control (BTS, 2016).

Patients are first categorised as having controlled, partly controlled or uncontrolled asthma (BTS, 2016; SIGN, 2016). The patient's HCPs determine this categorisation by examining several factors including, the frequency of symptoms, lung function, physical limitations and treatment needs (BTS, 2016; SIGN, 2016).

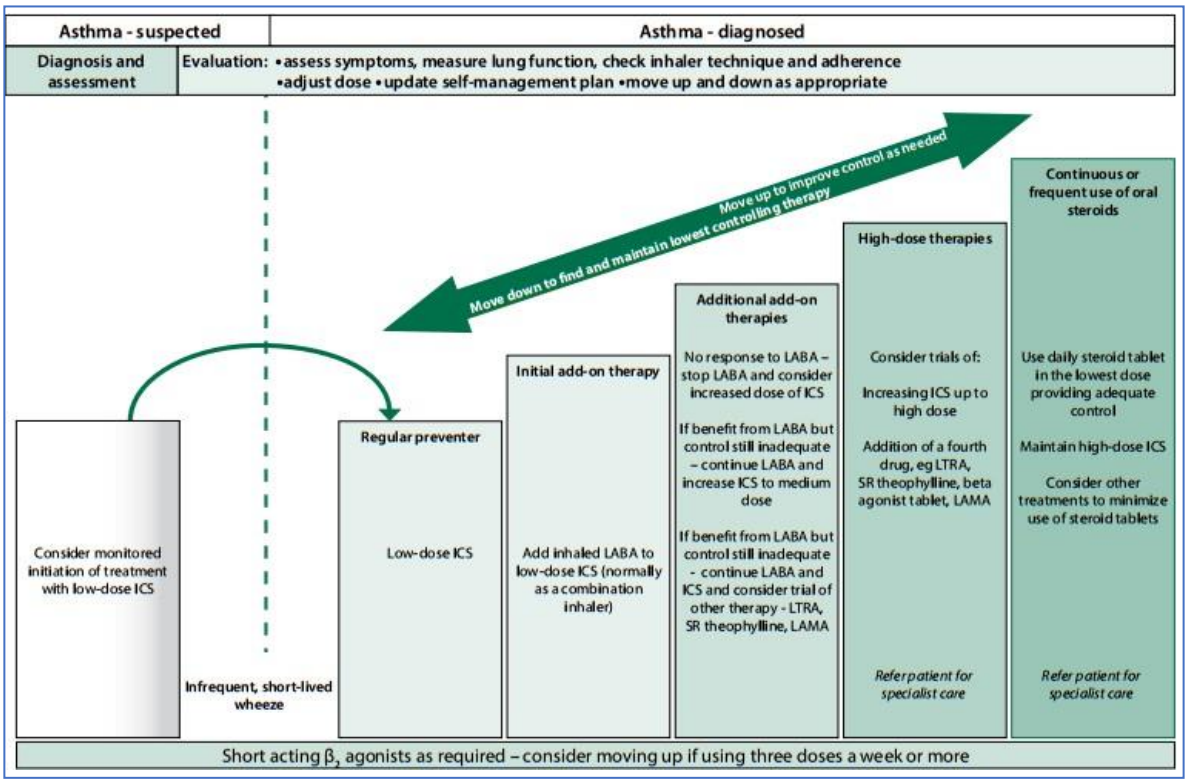

Figure 5. The current stepwise treatment approach for asthma in the UK (BTS, 2016; SIGN, 2016).

As Figure 5 illustrates, HCPs endorse the use of regular preventative inhaled corticosteroid therapy (ICS), or 'preventer' treatment, and a short acting beta agonist (SABA) or long acting beta agonist (LABA) bronchodilator, more commonly known as 'reliever' inhalers, for patients with asthma (BTS, 2016). Those who remain uncontrolled whilst on these medications are provided with increased ICS doses and/or the introduction of further medications until symptomatic control is achieved (Morrison, 2016).

It is common for patients with asthma to refer to their inhalers by their colour, instead of the inhalers purpose (Asthma UK, 2019a). This is believed to help patients differentiate between their

preventer (ICS) and reliever (bronchodilator) inhalers (Asthma UK, 2019a). Whilst most people with asthma respond well to these forms of therapy, it has been reported that 5-10% of people with asthma do not respond to these forms of treatment and experience persistent symptoms and frequent exacerbations (Murphy et al., 2012).

1.8.1 Non-pharmacological treatments

Although the medical pharmacological field has made substantial progress and developed new therapies to help people with asthma (Murdoch & Lloyd, 2010; Doeing & Solway, 2013), patients may look for non-pharmacological options to help treat their symptoms, including using breathing exercises (Cramer et al., 2014) or participating in yoga exercises (Freitas et al., 2013). The Alexander technique, for example, is a common form of a non-pharmacological physical therapy for people with respiratory problems, including asthma (Dennis & Cates, 2012; Freitas et al., 2013). The technique was developed to correct an individual's posture and naturally align the body using a series of movements (Dennis & Cates, 2012). It is believed to help ease the breathing process for people with asthma (Freitas et al., 2013).

1.9 Thesis terminology

The following section outlines the key definitions and terminology used throughout this thesis, including physical activity, exercise, sport, South Asian, culture, and ethnic and/or cultural identity.

Physical activity, exercise and sport

The terms physical activity, sport and exercise are used synonymously (Caspersen, Powell, & Christenson, 1985). According to Caspersen et al. (1985), the definitions of physical activity, exercise and sport differ.

Terminology	Definition
Physical activity	Caspersen et al. (1985) defined physical activity as any type of activity that involves physical exertion and any type of voluntary movement that helps burn calories. It involves activities that enable a person to work harder than normal.
Exercise	Similarly, exercise involves physical exertion and movements which help burn calories, although, exercise is formal, structured and often repetitive behaviour (Caspersen et al., 1985). Some examples of exercise include jogging, recreational swimming, cycling or aerobics (Caspersen et al., 1985).
Sport	Sport also involves physical activity and exercise, although sport also normally includes a set of rules to abide by, or to help the individual excel in specific athletic skills (Caspersen et al., 1985). Sport can be played individually or in teams, and are often but not always, competitive (Caspersen et al., 1985).

Table 3. Key terms (physical activity; exercise; sport), adapted from Caspersen et al. (1985, pp. 127- 128).

The amount of physical activity, exercise, or sport performed by an individual is normally defined by the interrelationship between the total dose of activity and the intensity at which it is performed (Powell, Paluch & Blair, 2011).

South Asia

The term 'Indian subcontinent' is often associated with the term 'South Asia' (Bhopal, 2007). The term 'subcontinent' relates to a:

> *"a large land mass somewhat smaller than a continent subdivision of a continent, which has a distinct geographical, political, or cultural identity"* (English Oxford dictionary, online, 2019).

For the purposes of the current research, the term 'South Asia' will be used, instead of 'Indian subcontinent'. The countries considered to be part of South Asia remain debatable (Razzaque, 2004; Anderson, Anderson & Cool, 2014; Mann, 2015). According to Pirbhai, (2009), the geographical area of South Asia, includes India, Pakistan, Bangladesh, Nepal, Bhutan and Afghanistan, as well as the islands of Sri Lanka and the Maldives. Modern definitions are consistent in including Afghanistan as part of South Asia, although, this has been contested, as some scholars consider Afghanistan to be part of the Middle East, rather than South Asia (Robbins, 2013).

South Asian

In the UK, the term South Asian refers to people who have South Asian ancestry, such as those with either Indian, Pakistani, Bangladeshi, and to a lesser degree, Sri Lankan, Nepalese, Maldivians, and Afghanistani heritage (British Sociological Association (BSA), 2011). Also, the term 'South Asian' highlights the migratory patterns of these ethnic groups (BSA, 2011). Individuals with South Asian heritage, who reside in the UK, are also known as 'British Asians' (BSA, 2011). The use of the term 'South Asian' in the UK, normally excludes those who have East Asian ancestry (e.g., Chinese, Korean, Japanese), who are usually defined as East and Southeast Asian British citizens. In the 2011 UK census, the term Chinese or Other is used to categorise these ethnic groups (Office of National Statistics, (ONS), 2011). In other countries, such as North America and Australia, the term 'Asian' is used to refer to individuals with East, or Southeast ancestry (Australian Bureau of Statistics, 2006; US Census Bureau, 2017).

According to the 2011 UK census, approximately 6.3% of the UK's population are South Asian. Table 4 below (p. 32) shows the UK population statistics for each 'South Asian' ethnic group.

Ethnic categorisation, according to ONS (2011)	UK population (%)
Indians	2.5%
Pakistanis	2%
Bangladeshis	0.5%
Sri Lankans	Unknown
Nepalese	
Bhutanese	
Maldivians	
Afghanistanis	

Table 4. 2011 UK census data (adapted from ONS, 2011).

Greater London is reported to have the largest South Asian presence (12.9%) in England, closely followed by the West Midlands region (13.4%) and the Leicestershire county (11.9%) (ONS, 2011). Within Leicestershire, Leicester is regarded as one of the areas with a high South Asian presence in England (29.9%) (ONS, 2011).

Bhopal (2004) argued that the term 'South Asian' does not acknowledge the diversity of groups within this category. In the 1991 UK census, for example, Indians, Pakistanis, Bangladeshis, Chinese or any other ethnic group(s) were considered as part of the 'Asian' category (ONS, 1991). In the 2001 census, this changed and the category of 'Asian' encompassed other groups, including 'mixed' or any other 'Asian' ancestry to reflect the diversity of this population (ONS, 2001). Yet, due to the increasing nature of a heterogeneous UK population, the 2001 UK census was criticised for excluding other ethnic groups including, 'Black African' (Aspinall & Chinouya, 2008). This led to further discussion about how the 2001 census could be modified to be more inclusive (Aspinall & Chinouya, 2008).

The 2011 UK census addressed the issue of inclusivity and developed the category of 'Asian/ Asian British', and included sub-categories of 'Indian', 'Pakistani', 'Bangladeshi', 'Chinese' and 'Other Asian' (ONS, 2011). The addition of Mixed and/or multiple ethnic group, with sub-categories of 'White and Black Caribbean', 'White and Black African', 'White and Asian', and 'Other mixed', also

helped reflect the diversity of an increasing heterogeneous UK population. These classifications have allowed UK residents to select what they believe to be, their ethnic identification, demonstrating that the UK census has acknowledged the diverse and fluid nature of personal identities. The changing nature of ethnic classifications in the UK 2011 census reveals the problematic issue of attempting to label individuals, whilst trying to incorporate diversity and fluidity of personal identities. In the current thesis, the terms 'South Asian', 'British Asian', 'Indian', 'Pakistani', 'Bangladeshi', 'Sri Lankan', 'Other Mixed' were used as these were the terms that the participants used to describe their own perceived ethnic and/or cultural identity. However, when citing published studies, the terminology referring to ethnic identification and/or identity corresponded with the terms used in the original study.

Additionally, the term 'South Asian' has come to indicate people who are either originally from the Indian sub-continent, or those who have ancestry from either India, Pakistan, Bangladesh, Sri Lanka, Nepal, Bhutan, Maldives, or Afghanistan. As a result, the creation of a collective identity has materialised; one which presumes that people from the Indian sub-continent have a common language, culture and religion, particularly in relation to Indians, Pakistanis and Bangladeshis. Yet, Singh (1994) argued that the UK South Asian presence is wholly heterogeneous:

> *"It is a popular misconception to place all people originating from India, Pakistan, Bangladesh and people with brown skin from East African countries in one category - Asian. To call them Asian assumes that they constitute one homogenous group. Indians, Pakistanis and Bengalis are separate communities in themselves with many variations within them. It is important to remember that cultural, regional, linguistic and religious diversity amongst these groups is very significant."* (p. 9).

Culture

The term 'culture' does not have a singular definition, rather there are several definitions (Grossberg, 1996). Golka (2009) suggested that:

> *"Culture is a set of patterns of behaviour, behaviours themselves and their products which are created, acquired, applied and transformed in the course of social life."* (p. 59).

The United Nations Educational, Scientific and Cultural Organisation (UNESCO) (2002) referred to culture as a:

> "*…set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyle, ways of living together, value systems, traditions and beliefs."* (p. 67).

Both share the view that individuals are influenced by their culture (UNESCO, 2002; Golka, 2009). From an anthropological standpoint, culture is referred to as "*a particular way of life, whether of a people, a period, a group, or humanity in general*' (Williams, 1983, p. 83). Brah (2006) perceived culture as "*the symbolic construction of the vast array of a social group's life experiences. Culture is the embodiment, the chronicle of a group's history"* (p. 18). In essence, an individual's culture plays a role in their thinking and behaviour and their values and traditions.

Cultural and/or ethnic identity

An individual's cultural and/or ethnic identity relates to his/her sense of self in terms of belonging to a specific ethnic group (Leibkind, 2006). Cultural and/or ethnic identity not only refers to one's group affiliation but also relates to several other aspects, such as self-identification or self-conception, membership or belongingness to his/her own ethnic group, shared values and attitudes towards the group (Leibkind, 2006).

Gamsakhurdia (2017) suggested that cultural and/or ethnic identity can be linked to a sense of belonging, based on an individual's ethnic ancestry, cultural heritage, values, traditions or traditional practices and rituals, and in some cases, language and religion. Verkuyten (2005) suggested that cultural and/or ethnic identity is different to other social identities because ethnicity is related to one's personal belief in his/her heritage or ancestry. Understanding where one comes from provides individuals with a significant feeling of belonging to a specific ethnic group; it makes up part of their identity (Verkuyten, 2005). According to Verkuyten (2005), cultural and/or ethnic identity does not necessarily need to be linked to one's culture. An individual's cultural and/or ethnic identity can be integral to his/her sense of self, yet cultural changes can occur. Verkuyten (2005) argued that this is because subjective beliefs associated with one's heritage are socially constructed. This means that these beliefs are subject to change and re-interpretation (Verkuyten, 2005). Further, cultural and/or ethnic identity is expressed in social interaction, meaning that it is dependent on the acceptance of others (Verkuyten, 2005). Terms used in this thesis are explained either within the context of the discussion, as footnotes, or in the

glossary.

1.10 Structure of this thesis

The thesis is divided into seven chapters.

Following this introductory chapter, chapter Two offers a critical discussion of the academic literature, which contributes to and helps contextualise the phenomena of UK-resident South Asian adults' experiences of asthma and sport and exercise.

Chapter Three provides an in-depth discussion of the conceptual frameworks used to contextualise the findings of this thesis (which are presented in chapter Five). This thesis used symbolic interactionism, in combination with a phenomenologically-inspired approach, to understand UK- resident South Asian adults' experiences of asthma and sport and exercise. The following theorists' insights were drawn on to analyse the lived experiences of asthma, sport and exercise; Goffman's (1959) presentation of self, Goffman's (1963) discussion of stigma, Leder's (1990) concepts of the absent body and 'dys-functional' body, and finally, Zeiler's (2010) notion of the 'eu-static' body.

Chapter Four discusses the methodological approach, justifies the chosen research method, and describes the process and participants in the study. As part of a reflexive approach to this research, my role as the researcher is also discussed. A discussion about arts-based representation, more specifically poetic inquiry, and how it was applied to some of the data is also included within this chapter.

Chapter Five is a combination of the main findings and a discussion of the previous literature. This chapter presents data from in-depth, face to face interviews with 14 individuals with asthma (12 females, 2 males), who self-identify as South Asian, and who have taken part in, or were currently engaging in sport and/or exercise. Seven key themes derived from the participants accounts are presented with quotations combined with in-depth interpretations and application of the theoretical insights from the theorists discussed in chapter Three (e.g., Goffman, 1959; 1963; Leder, 1990; Zeiler, 2010). The seven main themes presented are titled: Negotiating the asthmatic identity; Managing medication; Seeking non-pharmacological treatments; "Other South Asians are lazy": Challenging cultural standards; Managing sport and exercise; Experiencing cultural stigma and lastly, Relationships with healthcare professionals.

Chapter Six consists of eight poetic representations from some of the participants' data. The aim of this chapter was to show the reader a 'new and different way' of looking at the data in the context of this study.

The final chapter (chapter Seven) presents the conclusions and recommendations, offers some summative points about the thesis and provides implications for healthcare policy and further areas of research in this area.

Chapter Two: South Asian people's experiences of asthma and sport and/or exercise: Review of the literature

2.1 Introduction

Chapter One detailed the physiology, treatment and management of asthma, as well as the prevalence of asthma in UK South Asian groups. The introductory chapter also outlined the sport and exercise participation rates in UK South Asian groups, as well as the complexity of sports and exercise for people with asthma and the challenges asthma poses. This chapter locates the present study within the existing body of empirical literature and provides a comprehensive review of the literature related to the research question and objectives set out in the preceding chapter. This chapter begins by describing the strategy used to access the literature. Following this, a critical review of the limited body of empirical evidence on UK South Asian adults' experiences of asthma and sports and exercise is presented to contextualise the current research and illustrate its contribution to the present body of knowledge.

2.2 Literature search strategy

In October 2015, and updated in April 2019, an English language title search was conducted to identify published research that studied UK South Asian adults with asthma and their experiences of sport and/or exercise. As this was an exploratory study on a relatively under-researched area, the initial search was as broad as possible, and included international literature from disciplines including social science, nursing, psychology, medicine, anthropology, and both quantitative and qualitative approaches, in order to provide a comprehensive account of the literature. There were no imposed date restrictions. Appropriate search terms were created by reviewing abstracts, titles and key words from previous literature relating to the subject area that was already known to me, the researcher. The main terms used primarily were, "asthma", "sports", "exercise", "South Asian" and "adults". The definition of 'South Asian' was considered broadly; search terms included different ethnic groups, for example, "Indian", "Pakistani", "Sri Lankan", "Bangladeshi", "Afghanistan", "Nepalese", "Bhutanese" and "Maldivian". The initial search terms used were also expanded to include similar and related terms and were used together and entered in various combinations to each of the databases, using Boolean operators to efficiently connect the search terms (see Table 5, pp. 39-42). A total of 15 databases were searched. In addition, several key websites were examined, including Asthma UK, World Health Organisation (WHO) and Gov.UK for

related literature on the subject area.

The titles of the selected papers were first examined for relevance; where the title suggested relevance for the present study's objectives (see section 1.4). Abstracts were then reviewed. Only papers relating to South Asians' experiences of asthma, sports and exercise were included; papers examining other population's asthma experiences of sport and exercise were excluded, unless the paper was a comparison study that investigated both the South Asian and other populations. In addition, reference-chaining (Dixon-Woods et al., 2006) was used to help identify further literature. Alert systems were also set up for the duration of the present study to track newly published papers in the subject area.

The literature search yielded no results for "South Asian", "asthma", "adult", "sports", or "exercise" as its main focus. Given the limited amount of empirical work currently available, this review included papers that either had asthma and South Asian as the central focus, or sports and exercise and South Asian as the main focus and also included papers relating to childhood and adolescent South Asian asthma populations (e.g., Lal, Kumar & Malhotra, 1995; Cane, Pao & McKenzie, 2001; Hazir et al., 2002; Shivbalan, Balasubramanian & Anandnathan, 2005; Smeeton et al., 2007; Lakhanpaul et al., 2014; Lakhanpaul et al., 2015; Lakhanpaul et al., 2016; Banga et al., 2017; Lakhanpaul et al., 2017).

The literature search yielded a total of 15 articles that had asthma as the main focus (Lal et al., 1995; Cane et al., 2001; Griffiths et al., 2001; Hazir et al., 2002; Hussein & Partridge, 2002; Singh et al., 2002; Mishra, 2004; Shivbalan et al., 2005; Netuveli et al., 2007; Smeeton et al., 2007; Lakhanpaul et al., 2014; Lakhanpaul et al., 2015; Lakhanpaul et al., 2016; Banga et al., 2017; Lakhanpaul et al., 2017;) and 18 studies that had sports and exercise as the central focus (Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et al., 2000; SportScotland, 2001; Carroll et al., 2002; Rishbeth, 2004; Lawton et al., 2006; Netto et al., 2006; Openspace, 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008; Jepson et al., 2008; Keval, 2009; Ahmad, 2011; Babakus & Thompson, 2012; Jepson et al., 2012; Koshoedo et al., 2015; King & Little, 2017).

These publications have been thematically organised to illustrate the focus of asthma in the South Asian population, and sports and exercise. The resulting papers were then subjected to a critical review (pp. 44-76).

Databases searched	Asthma related terms	Boolean operator	Sports and exercise related terms	Boolean operator	South Asian related terms	Boolean operator	Social related terms
Academic Search Premier British Nursing database (formerly British Nursing Index with full text) CINAHL Plus with full text Cochrane Library COPAC eBook Collection (EBSCO)	Asthma	AND	Sport Exercise Physical activity Fitness	AND	South Asian OR British Asian OR Indian OR Pakistani OR Bangladeshi OR Sri Lankan OR Nepalese OR Bhutanese	AND	Experience Culture Attitudes Behaviour Embodiment Identity Cultural identity

Databases searched	Asthma related terms	Boolean operator	Sports and exercise related terms	Boolean operator	South Asian related terms	Boolean operator	Social related terms
Academic Search Premier British Nursing database (formerly British Nursing Index with full text) CINAHL Plus with full text Cochrane Library COPAC eBook Collection (EBSCO)	Asthma	AND	Sport Exercise Physical activity Fitness	AND	South Asian OR British Asian OR Indian OR Pakistani OR Bangladeshi OR Sri Lankan OR Nepalese OR Bhutanese OR	AND	Experience Culture Attitudes Behaviour Embodiment Identity Cultural identity

E-Journals Google Scholar International Bibliography of Social Sciences IngentaConnect Medline (EBSCO) PsycINFO PsychARTICLES Scopus Science Direct					OR Maldivian OR Afghanistan		

Sports Medicine & Education Index							
Web of Science (formerly Web of Knowledge)							
ZETOC							

Table 5. Databases used for the literature review.

The body of evidence providing further detail about South Asian's experiences of asthma and sport and/or exercise (the objectives of the current study) revealed the following themes:

- beliefs and understandings about asthma
- the stigma of asthma
- treatment beliefs
- non-pharmacological treatments
- interacting with healthcare services
- barriers towards sport and exercise
- gender differences in sport and exercise participation
- motivations and facilitators to exercise and sport

Each theme will now be explored in further detail.

2.2.1 Beliefs and understandings about asthma in the South Asian population

Shivbalan et al. (2005) study was based in India and explored the parental perceptions of asthma. Shivbalan et al.'s (2005) study was conducted in Chennai City in South India, and 100 parents of asthmatic children took part in an interview (mothers, n=63, fathers, n=37). Most of the respondents were part of the middle class (87%) and the majority of them lived in urban areas (urban 61%, semi-urban 26% and rural 13%). The results revealed that parental knowledge of asthma was poor. It was reported that more than half of the sample population had little knowledge about asthma and 54% of the respondents did not have any concept of asthma (Shivbalan et al., 2005). Only 3% of parents interviewed believed that asthma was an illness, which caused a narrowing of the airways (Shivbalan et al., 2005). A small number of respondents believed asthma was only prevalent in the elderly (Shivbalan et al., 2005). Banga et al. (2017) conducted a study to explore mothers' perceptions of asthma in India, and a total of 300 mothers were interviewed. It was reported that 26% of mothers thought that asthma was curable and 54% of mothers were unaware about the prognosis of their child's asthma. In Banga et al.'s (2017) study, it was stated that 12.6% of parents believed asthma was a curse from God. This was similarly found in Hazir et al.'s (2002) investigation, which examined carers' perceptions and management practices of childhood asthma in a selected Pakistani community living in Islamabad, Pakistan. In Hazir et al.'s (2002) study, parents believed that 'saya'/'nazar'[2]

[2] The evil eye is considered to be a curse cast by a malicious stare, normally given to a person when they are unsuspecting. Several cultures believe that the evil eye can cause injury, illness or misfortune. For example, the

(superstitions/evil eye) were responsible for their child's asthma.

Hazir et al. (2002) interviewed 200 carers of children with asthma and reported that asthma awareness was inadequate. A high proportion (n=178 (89%) of respondents believed that various types of food, such as oily foods, aggravated asthma. In response, many found abstinence from certain foods to be effective. This was supported by similar findings from Gautam et al.'s (2008) study, which was based in India. Gautam et al. (2008) conducted their study in Delhi, India and asked GPs' what they believed to be triggers of asthma for children. Gautam et al.'s (2008) study found that GPs with 5 years of practice or more held perceptions about asthma, including that drinking milk produces more mucous, and that children with asthma should avoid dairy products, chilled drinks, and sour or chilled foods. Gautam et al. (2008) reported that approximately 40% of GPs believed that certain foods, including chilled foods, sour foods, and foods containing dairy such as milk triggered symptoms of asthma. Although Gautam et al.'s (2008) study was based in one city of India and cannot be representative of the entire Southern region of the Asian continent, it has demonstrated some of the beliefs and understandings about asthma in India.

In Gautam et al.'s (2008) study, it should be noted that perceptions about asthma may have been linked to the education level and socioeconomic status of respondents. For example, among the respondents in Shivbalan et al.'s (2005) study, 73% were literate (able to read and write one language with understanding) and 27% of respondents were illiterate. In Banga et al.'s (2017) study, the sample population included 15% of mothers who were illiterate and 53.3% of respondents who had had not studied in high school. Furthermore, there was a higher number of respondents who lived in rural areas (59%), whereas 41% lived in urban areas. Hazir et al. (2002), however, reported that in their study, there were no prominent differences in the understanding of asthma between those at opposite ends of the education or economic continuum. This suggested that education awareness about asthma may not always be related to levels of education or socioeconomic status.

When compared with UK-based studies, there were both similarities and differences in understandings about asthma with the international literature. Hussein and Partridge (2002) investigated London-resident Indian and Pakistani adults with asthma, though, the respondents' level of education was not stated. Hussein and Partridge (2002) explored knowledge and perceptions about asthma from UK residents, who had migrated to the UK from Pakistan and India. In Hussein and Partridge's (2002)

evil eye is perceived to have caused weakness, fatigue, anorexia, diarrhoea, amongst other issues (Mull, Mull & Anderson, 1990; Hunte & Sultana, 1992).

study, it was reported that all of their South Asian participants held knowledge about the triggers of asthma and understood the symptoms and episodic nature of asthma. However, some of the participants were uncertain about what they believed to have caused asthma (Hussein & Partridge, 2002). A childhood asthma project which was aimed at developing a multifaceted intervention programme for the management of asthma (MIA project) (Lakhanpaul et al., 2014) investigated the perceptions of asthma among South Asian and White British families who resided in Leicester, UK. Data from in-depth interviews revealed that both South Asian and White British families described their understanding of asthma (Lakhanpaul et al., 2014). For example, the most commonly mentioned triggers of asthma were environmental, such as, the weather, damp, dust, pollen or pollution (Lakhanpaul et al., 2014). Also, Lakhanpaul et al.'s (2014) project shared some similarities with Banga et al.'s (2017) study. In Lakhanpaul et al.'s (2014) findings, South Asian groups in particular, believed that religion or fate were influential to the causation of their child's asthma. For example, Muslim respondents discussed God's will and Hindu respondents referred to Karma, as potential explanations that their child's asthma was envisioned for them (Lakhanpaul et al., 2014). In contrast, White British families in Lakhanpaul et al.'s (2014) study did not indicate that their child's asthma was associated with fate or any other religious perceptions. This suggested that there are specific views about the causes of asthma pertinent to South Asian groups.

Using their previous findings from the MIA project (Lakhanpaul et al., 2014), Lakhanpaul et al. (2017) interviewed parents and carers of South Asian and White British families two years after their previous investigation to further understand the perceptions and perceived barriers to asthma management in children with asthma. Lakhanpaul et al. (2017) used purposive sampling to ensure their sample was proportionately represented from what they believed to be the six main South Asian ethnic groups (Indian Gujarati Hindu; Indian Gujarati Muslim; Pakistani Muslim; Bangladeshi Muslim; Indian Punjabi Sikh and Indian Punjabi Hindu). In the MIA project (Lakhanpaul et al., 2014), the data from the interviews demonstrated that some South Asian groups believed their child's asthma to be fate, or destiny. Moreover, South Asian families often discussed how others in their community reacted when they were told about their child's asthma (Lakhanpaul et al., 2017).

Several South Asian families reported that others had reacted negatively when they were informed, including the fear that their child's asthma was contagious or that the condition was instigated by ineffectual parenting (Lakhanpaul et al., 2017). In complete contrast, none of the White British families involved in Lakhanpaul et al.'s (2017) study stated that asthma was contagious or that they had any experience of negative reactions from others. The view that asthma was 'contagious' was

commonplace in both UK-based (Lakhanpaul et al., 2014) and international literature in South Asian communities (Hazir et al., 2002; Shivbalan et al., 2005; Banga et al., 2017). It was a more commonly cited concern in the international literature. In a UK-based study by Hussein and Partridge (2002), many of the South Asian respondents believed that others in their community, including family and friends were supportive. The exception to this involved one male respondent who had not informed any of his family or friends about his asthma because *"…asthma was not accepted in the Asian society"* (Hussein & Partridge, 2002, p. 197), which suggested that asthma-related stigma was a concern for this respondent. Thus, the following section provides an in- depth investigation of the literature pertaining to the stigma associated with asthma in South Asian groups.

2.2.2 Stigma in the South Asian population

Smeeton et al. (2007) explored parental attitudes towards asthma management in the UK-resident population. This included parents from White British, Irish, or other White backgrounds, South Asian/South Asian British (such as, Indian, Pakistani, Bangladeshi or other South Asian group) and other ethnic groups, including Black Caribbean, Black African and those who identified as mixed ethnicity. It was unclear which South Asian communities Smeeton et al. (2007) considered to be part of the category 'any other South Asian group'. According to Smeeton et al. (2007), South Asian groups were unwilling to discuss some aspects of their child's asthma. For example, South Asian parents were more likely to be unhappy if their friends knew about their child's asthma and were less likely to inform their friends about their child's condition (Smeeton et al., 2007). The unwillingness to discuss their child's asthma was more likely to occur for South Asian parents who lacked post-secondary education, whereas this was less of a concern for South Asian parents who had post-secondary education (Smeeton et al., 2007). This finding demonstrated that there may be a link between South Asian parents' educational level and their reticence to discuss asthma with others. It was unclear, however, which specific South Asian groups Smeeton et al. (2007) were referring to. Thus, it cannot be determined whether this was as an issue for all of the South Asian groups involved in Smeeton et al.'s (2007) study, or whether this apprehension to inform others was prevalent in certain South Asian groups.

The MIA project by Lakhanpaul et al. (2014) reported that some of the South Asian parents were worried about the potential impact having asthma would have on marriage prospects for their children. For example, some parents stated that they would not agree to a marriage if they knew that their future son or daughter in law had asthma (p. 30). Another parent declared that they remained

constantly worried about whether the groom's family would discover that their daughter has asthma, and others stated that their son or daughter would be "*disregarded*" by others. The daughter in particular, was potentially "*disregarded*" because South Asian males looked for wives who were "*good and healthy*" and ones who would not pass illnesses such as asthma, onto their children (p. 30). The potential impact on marriage has also been demonstrated in the international literature. Similarly, to Lakhanpaul et al. (2014), Hazir et al.'s (2002) Pakistan-resident sample reported that there was an unwillingness to marry others with asthma to avoid passing it down to their children.

Furthermore, the fear that asthma is contagious is prominent in the international literature. For example, in Hazir et al.'s (2002) study, Pakistani carers of children with asthma were asked whether physical contact with someone with asthma exposed someone without asthma to an increased risk of developing the condition; 36.5% of the sample believed that it did. Investigations by Lal et al. (1995) and Shivbalan et al. (2005) which were based in India, found that over a third of their samples (34.1% and 35%) believed asthma is contagious. A more recent study by Banga et al. (2017) revealed that 29.3% of India-resident mothers shared the same belief. Banga et al.'s (2017) findings have demonstrated that in India, some South Asians continue to believe that asthma is contagious. In the UK-based literature, Lakhanpaul et al. (2014) found that some South Asian parents, mostly those from Indian Punjabi, Bangladeshi and Pakistani groups believed that asthma is contagious. Lakhanpaul et al. (2004) noted that this belief was related to misperceptions about the causes of asthma, and limited understandings about the condition.

For those who suffer from asthma-related stigmatisation, it can make it more difficult to manage and treat asthma for fear of being persecuted or being publicly associated with asthma. In Singh et al.'s (2002) study based in India, it was reported that there was a lack of acceptance of inhalers by Indian women, in particular. The acceptance rate for using inhalers was only 7% for Indian women (Singh et al., 2002). According to Singh et al. (2002), this is because Indian society is a male dominated society and having asthma is a barrier for marriage prospects. Thus, women concealed the diagnosis, and the treatment of asthma (Singh et al., 2002). A diagnosis of asthma for South Asian adults living in India may be considered stigmatising, possibly more so for Indian women (Singh et al., 2002). However, Singh et al. (2002) argued that it is possible that stigmatisation only occurs around the age of marriage for Indian women and around 40% of women preferred inhalers, compared to oral courses of treatment. This demonstrated that Indian women were becoming more accepting of inhalers (Singh et al., 2002), however, the study provided no

indication about whether men were stigmatised because of asthma, or whether they accepted the use of an inhaler. Similarly, Mishra (2004) argued that, for married adults, there is less stigma attached to asthma and it is not considered to be contagious. In the UK, Hussein and Partridge (2002) explicitly stated that none of their respondents had experienced stigma because of asthma.

Although Hussein and Partridge (2002) explored stigma in a UK-resident adult South Asian population with asthma, the study dates back 17 years. The most recent UK-based evidence was provided by Lakhanpaul et al. (2014), though, this was based on the parent's perceptions of perceived stigma. The UK-based literature has demonstrated that there is a focus on childhood asthma populations, leaving a gap in the area for further exploration into the experiences of adults with asthma, who reside in the UK and identify as South Asian. The next section (see section 2.2.3) investigates the literature related to the treatment beliefs and behaviours in the South Asian cohort, both in the UK and internationally.

2.2.3 Asthma treatment behaviours in the South Asian population

As discussed previously in section 1.2, the UK-resident South Asian population are at greater risk of hospitalisation because of their asthma. In turn, much of the evidence relates to the treatment behaviours and self-management of asthma in the South Asian population. Previous research from Griffiths et al. (2001), for example, investigated why there was an increased risk of asthma-related hospital admissions among South Asian groups in the UK. Griffiths et al. (2001) interviewed South Asian and White adults (n=58 in total, 49 admitted to hospital with asthma, 9 not admitted) with asthma, and 25 healthcare practitioners. The South Asian sample was restricted to UK-resident Indian, Pakistani, Bangladeshi and Sri Lankan groups (Griffiths et al., 2001). According to Griffiths et al. (2001), South Asian groups coped differently with asthma than their White counterparts. For example, some South Asians were less confident about controlling their asthma and were unaccustomed to using preventative medication (Griffiths et al., 2001). Additionally, there was a lack of understanding about the roles of preventer and reliever treatment in both the White and South Asian groups. However, it was more prevalent in South Asian groups; only one South Asian person with asthma understood the role of preventative medication (Griffiths et al., 2001). The use of preventer (or prophylactic) medication was absent from South Asians accounts (Griffiths et al., 2001). The notion of using preventer medication to decrease the chances of an asthma attack was described by only one South Asian male yet this was routine among the White group (Griffiths et al., 2001). Frequent use of the reliever inhaler medication is a significant indicator of poor asthma control (Paris et al., 2008; Butz et al., 2015), and a risk factor for asthma exacerbations (Patel et al.,

2013).

Non-adherence to asthma medication could be linked to various factors (Dima et al., 2015). The person with asthma might not understand the importance or significance of taking their medications regularly or they may not understand the proper inhaler technique to better control their asthma; this is known as unintentional non-adherence (Náfrádi et al., 2016). On the other hand, if the person with asthma understands the ramifications of non-adherence to medication, and is non-adherent because of their beliefs, this is known as intentional non-adherence (Náfrádi et al., 2016).

A poor understanding of asthma and the different roles of preventer and reliever treatment in South Asian groups has been described in other studies (Hussein & Partridge, 2002; Netuveli et al., 2007; Lakhanpaul et al., 2014; Lakhanpaul et al., 2017). Similarly, to Griffiths et al. (2001), Hussein and Partridge (2002) reported that respondents understood the use of bronchodilators and recognised that the use of reliever inhalers would improve their breathing patterns and inhibit asthma exacerbations. Some South Asian respondents, however, did not understand the role of inhaled steroids, which is more commonly referred to as the preventer inhaler. Others stopped taking the preventer inhaler because they believed that the inhaler had no perceived effect for them (Hussein & Partridge, 2002). Medication non-adherence and an uncertainty related to the regular use of inhaled steroids has been found in other more recent studies (Lakhanpaul et al., 2014; Lakhanpaul et al., 2017). Given the centrality of medication adherence and non-adherence in asthma outcomes, research has focused on the reasons why some South Asian groups with asthma choose not to adhere to their prescribed medications (Hussein & Partridge, 2002; Lakhanpaul et al., 2017).

One of the most common reasons South Asian groups chose not to use their prescribed medications was because they believed that their prescribed medication was unnecessary (Horne, 2006). This perspective was also commonplace among other populations, including the White population (Griffiths et al., 2001; Lakhanpaul et al., 2017). Hussein and Partridge (2002) explained that their respondents chose to stop taking their asthma medications because of the perceived inefficacy. Lakhanpaul et al. (2017) described several reasons why parents of children with asthma chose for their children not to adhere to medication. For example, in the South Asian groups, there was a lack of understanding about how to take some medications. Some respondents reported not using them when there was an absence of symptoms (Lakhanpaul et al., 2017). South Asian families were more likely to discuss the reasons why they did not administer medications to their child (Lakhanpaul et al., 2017). This was often because parents were concerned about the risk of over-dependence and

the side effects of certain asthma medications, such as inhaled steroids (Lakhanpaul et al., 2017). Both South Asian groups and White British families discussed being worried about side effects, however some of the South Asian families voiced their concerns about an extensive range of suspicions, according to Lakhanpaul et al. (2017). These concerns included *"children's growth, stomach problems, heart problems, addiction, reduced immunity, oral thrush, mood or behavioural issues, and reduced immunity due to drugs*" (Lakhanpaul et al., 2017, p. 5). One South Asian parent was concerned that asthma medications exacerbated their child's asthma (Lakhanpaul et al., 2017). The fear of dependence on asthma medication was not only pertinent for South Asian families. Lakhanpaul et al. (2014) reported that White British families were also worried about their children becoming dependent on asthma medication. This shows that concerns about treatment are not restricted to South Asian groups. An earlier study by Smeeton et al. (2007), which examined parental attitudes towards the management of asthma in several ethnic minorities, reported that there were differences between White parents and other groups. For example, South Asians and Black African and Black Caribbean parents were more likely to report a dislike for preventer medication and were often anxious that pharmacological treatment was addictive.

Hussein and Partridge (2002) argued that the apprehension to use daily medication can be further exacerbated when patients discover that medical intervention does not cure asthma. In Hussein and Partridge's (2002) study, one respondent expected that asthma could be cured, until his GP informed him that asthma could not be medically cured. In Singh et al.'s (2002) study, only 15% of respondents out of 1012 adults with asthma in India understood that asthma could not be cured. The rest of the respondents (857 (84.7%)) reported a belief that there was a cure for asthma and were unaware about the chronic nature of asthma (Singh et al., 2002). According to Singh et al. (2002), those who misunderstood the roles of asthma drugs or were unaware about the chronic nature of asthma were more likely to stop taking regular treatment and use non-medical therapies which claimed to act as permanent cures to asthma. The following section (see section 2.2.4) explores the non-medical forms of treatment endorsed by some South Asian groups in the literature and their reasons for choosing such therapies.

2.2.4 Non-pharmacological methods of treating asthma

According to Tseui (1978), Eastern and Western approaches to medicine differ. Tseui (1978) argued that the Western approach uses hypothetical deduction, where the hypothesis is derived from observations and a research plan is designed. When enough data has been collected, conclusions are drawn. The

Eastern approach, on the other hand, follows the inductive method and tends to be associated with a record of practical experience accrued from a number of practitioners throughout time (Tseui, 1978). The Western approach divides the health from the disease and healthcare practitioners are trained to treat acute phases of the disease. The Eastern approach, on the other hand, considers health as a balanced versus unbalanced state (Tseui, 1978) and resonates with traditional ways of treating illness, such as Ayurveda and Islamic medicine. The World Health Organisation (WHO, 2000) have described traditional medicine as:

> *"…the sum total of the knowledge, skills, and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness*" (p. 1).

Practices such as Ayurveda, Islamic medicine, traditional Chinese medicine, acupuncture and herbalism are some examples of the numerous types of traditional medicine created by different cultures to treat illness (Patwardhan et al., 2005; Petri, Delgado & McConnell, 2015). Mukherjee (2001) explained that traditional medicines in India are based on six systems of health, including the Ayurvedic system. This is the most widely accepted system according to Mukherjee (2001), and it has since been established as a comprehensive, medicinal system in South Asian countries, including India (Sen & Chakraborty, 2017). Ayurveda is a holistic system of healthcare and uses natural resources for the improvement of health (Mukherjee & Wahile, 2006). It is based on the notion that the human body consists of a medium of seven basic tissues; *"Rasa, Rakhta, Mansa, Meda, Asthi, Majja and Shukra and the waste products of the body, including faeces, urine and sweat"* (Mukherjee & Wahile, 2006, p. 26). These are believed to derive from the five basic elements, which include "*ether, air, fire, water and earth and three basic types of energies; vata, pitta, and kapha*" (Mukherjee & Wahile, 2006, p. 26). In Ayurveda, if there is an imbalance or disturbance of any of these basic principles, the body is thought to cause disease (Mukherjee & Wahile, 2006). The treatment approach to disease in this system is designed to balance the body's basic elements (Mukherjee & Wahile, 2006). Some research has suggested that some specific turmeric species can impact on specific pain receptors in the body and has been shown to be particularly effective for chest and abdominal pain (Bundy et al., 2004; Mills & Bone, 2012). This is because turmeric actively inhibits inflammatory pathways in the body (Mills & Bone, 2012). Thus, turmeric is often used as a traditional non-medical treatment in Ayurvedic practice (Prasad & Aggarwal, 2014). For example, in Pakistan, it is used as an anti-

inflammatory treatment and in India, it is used to purify the blood (Prasad & Aggarwal, 2014).

Other alternative treatment paradigms that are practised in South Asian countries, include Unani-Tibb medicine and homeopathy (Mukherjee, 2001; Mukherjee & Wahile, 2005). The Unani-Tibb system of healthcare was heavily influenced by Hippocrates (460-366 BC) (Mukherjee, 2001). Hippocrates introduced the 'humoral theory' of disease, which described the wet and dry characteristics of the different humours that constitute the human body (Mukherjee, 2001). One of the main principles of Tibb medicine is that the body has the ability to heal itself and therefore, therapies used in accordance with the Tibb philosophy must support this belief (Jabin, 2011). According to Keval (2009), traditional remedies are trusted by some South Asian communities to be effective towards treating illness and providing balance in the body. The latter is associated with Hippocrates's (born 460-370 BC) cold-hot theory of disease (Lloyd, 1964). Although the Western medical model has neglected Hippocrates' theory, it is present in other cross-cultural disease models including South Asian traditional medicines, Chinese medicine and other non-medical treatment approaches (Mukherjee, 2001). Hippocrates's theory is split into two stages. First, health beliefs are divided into hot or cold diseases (Becker, 2003). For example, asthma is believed to be a cold disease because it is linked to cold exposure and increased mucous production and is therefore considered a cold illness. Cold illnesses are treated using hot remedies and vice versa (Becker, 2003). Singh et al.'s (2002) explained that symptoms relating to asthma such as the common cold or a cough can be treated using hot remedies which include, cinnamon powder and honey mixed in warm water, or boiling leaves of basil, black peppercorns, crushed cloves and crushed ginger in piping hot water.

Recent evidence has indicated similar opinions exist in the UK. In Lakhanpaul et al.'s (2017) study, South Asian parents were reported to more often, try and find different methods to treat their child's asthma. For example, some South Asian parents stated that they would adapt their child's diet, as a form of asthma management (Lakhanpaul et al., 2017). This included avoiding cold foods, such as, ice cream, and providing the child with warm, or hot foods instead (Lakhanpaul et al., 2017). In addition, and in line with the Ayurvedic system of healthcare, some South Asian families considered the 'hot' and 'cold' properties of different foods, which might disrupt the physical and mental status of the body (Lakhanpaul et al., 2015; Shroff, 2017). In Griffiths et al.'s (2001) study, some South Asians discussed using traditional medicines or changing their diet to fit with the Ayurvedic humoral system. In Ayurveda, it is recommended to consume hot food spices such as ginger or turmeric to help treat asthma, reflecting the view that cold foods can lead to deterioration of condition (Griffiths et al.,

2001).

Parents of children with asthma in India also tended to search for alternative treatments to use (Banga et al., 2017). Singh et al. (2002) reported that, at the time of an asthma attack, many of their respondents sought to alleviate symptoms by using treatments they had made at home. According to Singh et al. (2002), hot substances, such as tea, were used to provide relief by almost half of the sample. Other ingredients including ginger, turmeric, cloves, sugar crystals and light meals were also believed to be provide relief, although, an explanation as to how these substances provided relief was not provided by Singh et al. (2002). Other research (Hazir et al., 2002) conducted in Pakistan, reported that whilst most of their sample were comfortable visiting a doctor, 9% also felt comfortable visiting a traditional practitioner known as a hakim and 11% felt comfortable practising homeopathy as a viable treatment option for their child's asthma. The reasons why they consulted these practitioners, however, were not stated in Hazir et al.'s (2002) study. Studies (Lal et al., 1995; Singh et al., 2002) which have investigated the treatment behaviours of adult South Asians with asthma in India have found that over half of asthma patients (65%) preferred to seek treatment outside of the hospital, whilst another study found that 79% of Indian parents preferred to use alternative therapies such as yoga and Ayurvedic treatments. Similar to Hazir et al.'s (2002) study, Singh et al.'s (2002) study did not indicate why their samples chose to use a non- pharmacological approach to treat asthma. It is difficult to compare UK-based evidence with the international literature. This is because many of those living in less urbanised countries than the UK, have different socioeconomic circumstances to UK-resident South Asians and also have limited access to healthcare. For example, it has been suggested that the costs of preventative medication can contribute to the decision to use non-pharmacological treatments, which can be accessed for a lower cost in India (Sarvesh et al., 2018).

In Hussein and Partridge's (2002) UK-based study, all of the respondents were aware of alternative treatments for asthma, though only one respondent discussed drinking ginger juice to help alleviate their symptoms. Another respondent reported a belief that a hakim in Pakistan had cured her nephew of asthma, although she would only visit a hakim if her condition deteriorated (Hussein & Partridge, 2002). One respondent stated that she swallowed a live fish whilst in India, after being encouraged by her mother to do so (Hussein & Partridge, 2002). An article in the Telegraph explained that, in India, asthma sufferers eat live fish combined with a yellow herbal paste, with the hope that it will help them breathe easier and, in some cases, permanently cure them of asthma (Henderson, 2014). Right groups and healthcare professionals have argued however, that this treatment is unscientific and a violation

of human rights, as well as being unhygienic (Henderson, 2014).

Hussein and Partridge's (2002) study also revealed that all of the respondents would try alternative treatments if their condition worsened and if their inhalers were considered to be ineffective. Recent evidence from Lakhanpaul et al. (2017) explained that although both White and South Asian families used non-pharmacological methods to treat their children's symptoms, South Asian families were more likely to take extra direct measures including keeping them warm and rubbing or massaging their backs. The evidence has demonstrated that UK South Asians share similarities with those in India and Pakistan, yet, there is a lack of UK-based literature that has investigated South Asians who live in the UK, and who migrated from an early age or were born in the UK. There is also a scarcity of research which has involved Bangladeshi or Sri Lankan South Asians in their studies. Much of the literature is restricted only to Indian and Pakistani South Asians; the reason for this is unknown. Therefore, to develop a broader understanding of a range of South Asian groups, the current research included UK-born, or early migration adults from Indian, Pakistani, Bangladeshi and Sri Lankan backgrounds.

Additionally, some evidence has indicated that some non-pharmacological treatments are embedded in religious cultural beliefs (El-Wakil, 2011). For example, people with an Islamic background have used cupping therapy[3] to treat ailments and illnesses (El-Wakil, 2011). There are two types of cupping; wet cupping and dry cupping (El-Wakil, 2011). Dry cupping involves placing a heated glass or cup onto the skin, whereby the air is drawn out, creating a space for the blood to flow and to stimulate bodily energy (Pachter, 1994; El-Wakil, 2011). Wet cupping, on the other hand, which is also referred to as 'blood cupping' is similar to dry cupping, however the practitioner also makes small incisions in the skin, in order to help the patient be free of blood stasis[4] (El-Wakil, 2011). From a medical perspective, cupping can act as physiotherapy for the chest (Clinkscale et al., 2012). However, there is a lack of published evidence which has investigated the use of such treatments for asthma in the UK-resident South Asian adult population.

[3] Cupping has original roots in traditional Chinese medicine (TCM) and has been an integral part of TCM for centuries (El-Wakil, 2011).

[4] Blood statis, or blood stagnation, is described as a condition which slows the blood in the body, causing pain and other symptoms (Neeb, 2006). It is an important underlying pathology of several diseases, according to traditional Chinese medicine (Neeb, 2006).

The studies which have been cited have indicated that some South Asian groups both in the UK, and in India and Pakistan, opt to use traditional remedies to help treat their asthma. However, some of these studies are based in India or Pakistan (Hazir et al., 2002; Singh et al., 2002), where it has been reported that preventative medication is less accessible than traditional treatments (George & Topaz, 2013). In contrast, treatments made from easily accessible products for adults with asthma in India are inexpensive (George & Topaz, 2013). The studies which were based in the UK (e.g., Hussein & Partridge, 2002; Lakhanpaul et al., 2017) did not mention the lack of accessibility as a possible reason for using non-pharmacological treatment. However, this could be because Lakhanpaul et al.'s (2017) study involved parents of children, where in the UK, prescriptions for asthma treatment for people under the age of 16, and from ages 16-18 if in full time education, do not require payment (NHS, 2017a). Although Hussein and Partridge's (2002) study involved South Asian adults with asthma, their sample was restricted to people with India and Pakistani heritage, and thus, did not consider the views of Bangladeshi or Sri Lankan adults with asthma. The study (Hussein & Partridge, 2002) is also 17 years old, and did not include a sample of South Asian adults who had been born in the UK. Instead, the sample was limited to South Asians who had migrated from India and Pakistan.

Previous research (Ali, Atkin & Neal, 2006; Rhodes et al., 2008; Samanta, Samanta & Madhloom, 2018), has argued that the biomedical paradigm, which has informed healthcare professionals in Western populations, has not adequately reflected the diversity of traditional treatment practices in the South Asian population; an aspect that might be integral to their culture and has evidently influenced the treatment of asthma in UK South Asian populations (see Hussein & Partridge, 2002). Thus, to gain a better understanding of South Asian cultural practices, the current research explored how these cultural beliefs are incorporated into people's lives, and more specifically, their management of asthma. The next section (see section 2.2.5) explores the interactions with healthcare professionals in the South Asian cohort.

2.2.5 Interactions with healthcare services in the South Asian population

When an individual is diagnosed with asthma, they enter a relationship with a clinician/healthcare professional (HCP), such as a general practitioner (GP), asthma nurse or other health worker such as a consultant or pharmacist (Asthma UK, 2018a). The partnership between a patient with asthma and their HCP is a professional, therapeutic-style, interpersonal relationship, which is intended to help the patient adhere to their treatment regimen to improve control of their asthma (Geppert & Collazo, 1998). Partnership between HCPs and patients involves working *"…together towards a mutually*

defined purpose" (Hook, 2006, p. 137) and is supported "*…by shared decision-making and knowledge, respect, reciprocity, communication and autonomy"* (Macdonald, Irvine & Smith, 2015, p. 3529). Central to the social roles of illness are the exchanges between HCPs and patients (Begum, 2015). There are two main types of HCP-patient interactions; doctor-centred and patient-centred interactions (Begum, 2015). Doctor-centred interactions are HCP-led and paternalistic, where the doctor is perceived as the provider of care, and the patient is seen as a passive recipient (Begum, 2015). Decisions are made about the patient and communicated to them in a direct, authoritative way (Begum, 2015). More recently, there has been a shift towards patient-centred care, where the HCP-patient consultation is based on open communication, listening, and exploring the patient's experiences to understand more about the patient's illness trajectory (Begum, 2015). Patients are encouraged to be actively involved in their care (Begum, 2015). The concept of concordance, which is described as a 'therapeutic alliance' between the HCP and patient, where decisions about treatment are shared, is fundamental to the patient-centred approach (Begum, 2015).

A therapeutic relationship is defined as one which is perceived as caring, supportive and embedded in a safe, comfortable and non-judgemental environment (Mottram, 2009). These relationships can extend over a period of time, or last briefly (Priebe & McCabe, 2006). A therapeutic relationship is one which demonstrates friendliness, genuine interest, and empathy, along with the desire to facilitate and support patients (Cousin et al., 2011). Consequently, these types of relationships engender an ethos for interactions which facilitate effective communication between the patient and their HCP, and are, thus, considered as the primary component of positive patient-healthcare professional experiences (Newell & Jordan, 2015). Chipidza, Wallwork and Stern (2015) argued that the HCP-patient relationship involves vulnerability and trust and it can be one of the most meaningful relationship for individuals. A trusting relationship between the patient and HCP evokes *"a feeling of working together to achieve the aim of better [asthma] self-management"* (Pinnock et al., 2015, p. 2). According to Kornhaber et al. (2016), a therapeutic interpersonal relationship can enhance the patient's experience of illness. To do this effectively, HCPs must therapeutically engage with their patients and focus on patient-centred care or adopt a patient-centric approach to improve health-related outcomes (Kornhaber et al., 2016). The Global Initiative for Asthma guidelines (GINA) (GINA, online, 2018) state that the patient-centric approach is one where the patient is encouraged to work with their HCP by getting involved in discussions about treatment and expressing his/her concerns in the consultation.

Studies in Western contexts have demonstrated that open communication and mutual understanding during consultations, or a partnership-style consultation between HCPs and patients can improve the delivery of healthcare **(**Maguire & Piceathly, 2002; Claramita et al., 2013). Studies in non-Western settings, including South Asia, have shown that this type of consultation is preferable (Moore 2009; Claramita et al., 2011), yet a different communication style may be more appropriate because social hierarchy is more prominent in this part of the world (Claramita et al., 2011). Doctors are considered to be of high status in the hierarchy and are due respect (Claramita et al., 2011). In India, one of oldest civilisations, the doctor-patient relationship has not changed, and a paternalistic approach continues to dominate, particularly because of the high status of doctors in their society (Scully & Wilson, 2019). Cultural aspects such as these, may contribute to a paternalistic style of communication, where the doctor dictates the consultation because of their perceived higher social status. It has also been argued that in Asian countries, partnership between the HCP and patient is about the doctor demonstrating a caring attitude towards the patient, more so than effective communication, which is often the focus in Western societies (Moore, 2009).

Qidwai (2003) conducted a questionnaire-based study of 420 adults to investigate patients' perceptions of medical practice in Pakistan. Many of the responses alluded to a paternalistic-style of medicine being practiced, for example, the belief that a *"…doctor is next to God"* (p. 296) was a feature of paternalistic medical practice. Other studies conducted in Pakistan demonstrate that patients often request their doctor to decide on the best course of action for them because of their high status in society (Jafarey & Farooqui, 2005). Thus, the significant role of individual autonomy is challenged in Eastern cultures (Kerry, 2000). Jafarey and Farooqui (2005) explained that in the Pakistani context, patients are less willing to participate in discussions about their treatment and are more likely to delegate family members or trust their HCPs to make the decisions. Moazam (2000) proposed that a triad exists in Pakistani society, which includes the family, HCP and patient. The traditional way of living with extended families often means that the role of the family is inherently important in decision making situations, including making decisions about medical treatment.

A study in Nepal by Moore (2009), who interviewed medical students about patient-centred communication revealed a significant difference between the attitudes voiced by the medical students and the way they believed medicine was being practiced in Nepal. Similar to Qidwai's (2003) and Jafarey and Farroqui's (2005) findings, Moore (2009) found that doctors were held in great respect by Nepalese patients, often more so by poorer patients. There was also a hierarchy of doctors, where patients sought to consult with the most senior doctor. The most prestigious doctors

were held in high esteem and were met with unquestioned obedience from patients. Medical students unanimously agreed that doctors should treat patients with respect and as equals, encouraging patients to adopt an active approach in the consultation, and that this can be achieved if the doctor remains in control of the consultation. Moore's (2009) study revealed, however, that patients were reluctant to take an active role, and that many doctors did not approach the consultation with a patient-centred approach.

Patients were also uncomfortable opening up about their personal issues, and some suggested that patients would be more willing to do so if they were given the opportunity to speak freely (Moore, 2009). According to some respondents, patients disliked making decisions and wanted to give decision-making responsibilities to their doctors or their family members, even after doctors offered them guidance and encouraged them to make their own decisions (Moore, 2009). According to Moore (2009), a lack of education played a role and was considered a barrier to clear communication. Patients, for example, were uncertain about what to ask during consultations, and doctors found it difficult to offer guidance to less educated patients. It was thought that some doctors did not respect patients and were unwilling to listen, although this was attributed to lack of time and over-prescribed healthcare services (Moore, 2009). In complete contrast to the UK's healthcare system, Nepalese patients are required to pay for their treatment, and this impacts how they are treated. Moore (2009) explained that doctors' attitudes towards a patient was dependent on their social and economic position. Caste, however, was not considered important. Moore's (2009) results reflected the hierarchical nature of the Nepalese healthcare system, where patients' financial, societal and educational status influenced the type of care they received. Moore (2009) also reiterated that Nepalese patients visited doctors who practiced western medicine, to provide them with a 'cure', and that patients wanted their medical issues to be 'fixed', instead of focusing on preventative health measures. A recent study, however, has shown that doctors and nurses in Nepal disagree with paternalistic attitudes towards medicine, signalling a shift in perspective in certain non-Western contexts (Adhikhari et al., 2016).

In the UK, studies have reported on patients' experiences of care (Vydelingum; 2000; Griffiths et al., 2001), though, there are different issues to those in non-Western settings. In Vydelingum's (2000) study on South Asian patients experiences of hospital care in the UK, it was reported that some patients felt satisfied about their stay in hospital. Others, however, felt out of place and attempted to *"fit in"* (p. 103) with what was perceived as an 'English' place. Some patients described their stay in hospital as *"passing through"* (p. 103), and that they were only there for a short time yet

expressed several issues. Attitudes towards religion and culture were believed to be neglected by HCPs, and some patients did not expect their HCPs to understand much about their religious and/or cultural background. As part of their strategy to 'fit in', patients adopted different strategies, so not to disturb the routine for others on the ward, such as, reading their holy books silently (Vydelingum, 2000). Comments from patients suggested that they were not expecting staff to make any special considerations for them.

Other strategies to *"fit in within an English place"*, included wearing pyjamas and hospital gowns instead of traditional clothing, as a way of conforming to the expected standard. According to Vydelingum (2000), this conformity demonstrated a *"child-like trepidation"* (p. 103) of established rules and regulations within the UK hospital environment. Patients attempted to obey these rules, particularly the rule to have no more than two visitors at a time and expressed embarrassment when they were reprimanded for disobeying this rule. When family or friends were not present, some patients felt isolated and lonely. This feeling was exacerbated when they were unable to speak to their HCPs due to language barriers. Such communication difficulties were compounded by the HCP's lack of concern towards providing the resources to improve communication. This served to heighten the patients sense of alienation and helplessness. When they were discharged, some patients believed that they had not received enough information, or advice about their condition. Instead, they coped by visiting their local pharmacist, the local GP surgery and family and friends. The local pharmacist and GP often spoke the same language, thus, a reciprocal and cooperative relationship existed between the local services and the patient. Vydelingum (2000) argued that hospital HCP staff should be aware of the isolation and loneliness felt by ethnic minority patients due to language barriers, to ensure that the correct provisions are put in place to improve communication, and to inform patients pre-discharge. This may also help South Asian patients feel more comfortable about 'fitting in' within the UK hospital environment. Vydelingum's (2000) study, however, was based on a sample population of South Asian adults who had migrated to the UK and did not include British born South Asian adults. It was therefore unclear whether the latter would share similar issues with non-born UK residents when they are admitted to UK hospitals.

Other cultural characteristics which may affect the HCP-patient relationship include the use of traditional medicine (see section 2.2.4 for a discussion about non-pharmacological methods of treatment). A study by Singh, Raidoo and Harries (2004) revealed that among the Indian community in South Africa, many patients used traditional medicines, yet some failed to notify their HCPs about it. It was established that 53.6% believed it was unnecessary to inform their HCPs about their use of

traditional medicines, 7.1% believed their doctor might become upset if they revealed this information and 28.6% argued that their doctor did not enquire about other treatments, or take a medical history of non-pharmacological treatments. A similar issue was revealed in a study conducted in Pakistan, where it was reported that 63% of people believed in the benefits of traditional medicine and 58% preferred it over western medicine (Amin, Islam & Gilani, 2015). The latter, however, was primarily because traditional medicine was cost effective. It was also revealed that approximately 85% did not feel the need to inform their doctors about their use of traditional medicine (Amin et al., 2015).

In the UK, Maha and Shaw (2007) found that discussion about traditional medicines was considered unusual by the GPs' they interviewed, and that any discussion was generally initiated by the patients. It was acknowledged that patients may be worried about disclosing such information if they fear their doctors are sceptical about the use of non-pharmacological treatments. This mirrors research by Singh et al. (2004), and by Stephenson et al. (2003), who found that patients did not disclose their self-care practices and other methods of treatment because of fears and concerns about their HCP's response. Traditionally, there has been a hostile relationship between traditional methods and western orthodox medicine, and this may be why patients conceal their use of such treatments from their HCPs (Bjermer, 2005).

In Griffiths et al.'s (2001) study, it was revealed that some South Asian patients used complementary therapies and other traditional forms of treatment in conjunction with their prescribed medication. Griffiths et al. (2001), however, did not state whether this information was disclosed or concealed from HCPs during asthma consultations. Instead, Griffiths et al. (2001) investigated the relationship between patients and HCPs, where it was reported that respondents held distinct opinions about their HCPs. Griffiths et al. (2001) explained that although both White and South Asian groups had negative experiences with their GPs, there were differences pertinent to each of the groups. For example, some of the White respondents had a personal relationship with their GP and were on first name terms (Griffiths et al., 2001). These respondents valued continuity and personal care (Griffiths et al., 2001). In the accounts of South Asian patients however, this acquaintance-style relationship with GPs' was not reported (Griffiths et al., 2001). Instead, South Asian respondents stated that they had less personal and more functional relationships with their GPs (Griffiths et al., 2001). For example, South Asian respondents were satisfied when their GP's spoke the same language as them, and who would check in on them either by a face-to-face visit at home or via telephone (Griffiths et al., 2001). Additionally, Griffiths et al. (2001) found that the South Asian adults who were confident

about managing asthma and understood their treatment experienced positive relationships with their GPs'. It was unclear, however, whether this was because the GP in question provided greater engagement with these patients, or whether the GP provided a better consultation than those who experienced negative relationships with their GPs.

Unlike Griffiths et al.'s (2001) study, Hussein and Partridge's (2002) sample consisted only of South Asian patients. Hussein and Partridge (2002) reported that many of the respondents were unhappy with the way some GPs treated them. Several respondents perceived their GPs as being unhelpful and not providing adequate information about asthma (Hussein & Partridge, 2002). The majority of the respondents also felt that their GP did not provide enough information about asthma when they were diagnosed (Hussein & Partridge, 2002). Others expressed their dissatisfaction when they were unable to see their GP when their condition deteriorated (Hussein & Partridge, 2002). In contrast, all of the respondents, were content about the advice and guidance received from other healthcare professionals, including nurses, pharmacists and A&E departments (Hussein & Partridge, 2002), which indicated that their discontent was directed towards their GPs only.

Similarly, investigations in childhood populations with asthma (e.g., Cane et al., 2001; Smeeton et al., 2007; Lakhanpaul et al., 2015; Lakhanpaul et al., 2016) have found that South Asian parents were less satisfied with the service offered by their GP and were more content with hospital services and with other healthcare professionals. Smeeton et al. (2007) argued that there was a possibility that their respondents were less satisfied because they dealt with inexperienced GPs', which subsequently led them to have greater confidence in hospital services, instead of their GP. In Cane et al.'s (2001) study of Bangladeshi mothers of children with asthma, some mothers mentioned that attending A&E was preferable to visiting their GP. This was because GPs' were considered to be unhelpful and were seen only if their symptoms were perceived to be serious (Cane et al., 2001). It was unclear in Cane et al.'s (2001) study what symptoms were deemed to be serious by GPs'. Cane et al.'s (2001) results could be interpreted to mean that the mothers in their sample believed that their child was ill and subsequently sought assistance from their GPs' for further treatment. The GP, however, did not consider the child to be ill to necessitate further treatment or assistance.

In Lakhanpaul et al.'s (2015) investigation where both South Asian and White British families were interviewed, it was reported that both groups sought further information about asthma from their HCPs; 19 out of the 30 South Asian families requested that they would have liked more advice about how to manage asthma for their child. In a further investigation, Lakhanpaul et al. (2016) interviewed

South Asian parents with asthma of Indian, Pakistani and Bangladeshi descent, who explained that practice nurses were more adept at providing information about asthma because they dedicated more time and focus to the parents than GPs. Lakhanpaul et al. (2016) did not specify whether the information gathered by practice nurses helped the parents to manage their child's asthma. It is possible that the parents of children with asthma visited practice nurses because their child was ill and saw improvement when they attended, thus, perceiving practice nurses to be more adept.

It was unclear how the patient-clinician relationships affected the outcomes of care and whether the type of care influenced asthma self-management behaviours (Cane et al., 2001; Griffiths et al., 2001; Hussein & Partridge, 2002; Smeeton et al., 2007; Lakhanpaul et al., 2015; Lakhanpaul et al., 2016). The evidence (Griffiths et al., 2001; Hussein & Partridge, 2002; Cane et al., 2001; Smeeton et al., 2007; Lakhanpaul et al., 2015; Lakhanpaul et al., 2016) has, however, demonstrated that interactions between patients and their HCPs are an important component of health care delivery and further insight is required to understand the complex and dynamic nature of such interactions, with a focus on the qualities and characteristics of the patient-provider relationship which influence both the patient-provider relationship and the outcomes of care for South Asian groups with asthma.

There was also no mention of the clinician's role of support in regard to sport and exercise behaviour in any of the studies (Cane et al., 2001; Griffiths et al., 2001; Hussein & Partridge, 2002; Smeeton et al., 2007; Lakhanpaul et al., 2015; Lakhanpaul et al., 2016). Presumably, this is because the studies were focused on investigating other issues pertinent to the role of the healthcare professional in asthma care, such as, the effectiveness of the clinician's service (Cane et al., 2001; Griffiths et al., 2001; Hussein & Partridge, 2002; Smeeton et al., 2007; Lakhanpaul et al., 2015; Lakhanpaul et al., 2016).

One study which explored HCPs' perceptions of exercise was from Gautam et al. (2008). A quantitative, cross-sectional study by Gautam et al. (2008), which examined GPs' knowledge of childhood asthma in Delhi, India reported that very few GPs' (20.4%) knew how to prevent exercise-induced asthma, though they did cite measures, such as, doing warm up exercises, avoiding trigger factors, taking medication before exercise, and doing respiratory exercises. However, out of 157 GPs' involved, 38% of GPs' reported measures, such as, avoiding exercise, and 19% of GPs' recommending swimming as the only exercise for children with asthma (Gautam et al., 2008). This study (Gautam et al., 2008), however, was based in India where the GPs' were trained. Gautam et al.'s (2008) investigation was also based on the GPs' perspective, instead of the patients' perspective. There was, therefore, no information provided about the patients' experiences of asthma, sport and exercise.

Thus, the role of the clinician from the patient's perspective, specifically in regard to sport and exercise behaviour, has been relatively limited for UK-resident South Asian adults with asthma.

It is with this that the next section (see section 2.3) of this review of literature moves onto the combination of asthma, sport and exercise in the South Asian population. Currently, there remains very little evidence, with only four studies providing a mention of sport or exercise in their investigations of asthma (Hussein & Partridge, 2002; Singh et al., 2002; Gautam et al., 2008; Poongadan, Gupta & Kumar, 2016). A further study by Lawton et al. (2006) has also been included, although, their investigation mainly focused on the experience of diabetes in the South Asian population, where asthma was mentioned only as a co-morbid condition to diabetes.

2.3 Asthma and sport and exercise in the South Asian population

An Indian case-controlled study for a period of one year (between 2014-15) by Poongadan, Gupta and Kumar (2016) investigated the link between lifestyle factors and asthma in a representative Indian population. The results showed that the sample lived a sedentary lifestyle and were less likely to take part in exercise to avoid contact with allergens, when compared with non-asthmatic people. The study (Poongadan et al., 2016) did not provide any other reason for the lack of participation and acknowledged that their study sample did not include a broad age group and was not culturally diverse, which could have made a difference to the results. Singh et al. (2002), who conducted a quantitative cross-sectional study in India, investigated South Asian adults' barriers to asthma management and their use of complementary treatment approaches. It was reported that physical activity, such as walking, provided relief for some, although rest and sitting was also found to be beneficial for others (Singh et al., 2002).

In a qualitative study that used a UK-resident South Asian Indian and Pakistani sample with Type 2 diabetes, Lawton et al. (2006) investigated the barriers towards physical activity and exercise. Lawton et al.'s (2006) findings suggested that some respondents referred to co-morbid conditions, including asthma, as a barrier towards participation. According to Lawton et al. (2006), respondents claimed that symptoms such as breathlessness made it difficult to engage in activities. It is unclear however, whether breathlessness was caused by asthma or another co-morbid condition described by respondents. Lawton et al.'s (2006) study also only included UK resident South Asians over the age of 40 and restricted their South Asian inclusion criteria to Indian and Pakistani adults, which limited the representativeness of the sample.

In Hussein and Partridge's (2002) study, there was a small mention of exercise participation in their investigation of UK South Asian adults with asthma. It was reported that asthma was a barrier for sport and exercise for South Asians with asthma. The isolated discussion itself in Hussein and Partridge's (2002) study was under the heading, 'dislikes about asthma', where one respondent stated that asthma prevented him from swimming and going to the gym. Hussein and Partridge (2002) did not provide any further discussion regarding sport and exercise participation. Thus, an exploration of the experiences of asthma, sport and exercise in the South Asian cohort remains limited in the published evidence. Instead, the evidence has focused on the barriers and motivations to physical activity, sport and exercise in the South Asian population. The subsequent section (see section 2.3.1) investigates the reasons why some South Asian groups are less likely to engage in physical activity, sport and exercise, though, this is not in relation to asthma.

2.3.1 Barriers towards exercise and sport participation for South Asian adults

Much of the evidence (Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et al., 2000; SportScotland, 2001; Carroll et al., 2002; Rishbeth, 2004; Lawton et al., 2006; Netto et al., 2006; Openspace, 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008; Jepson et al., 2008; Keval, 2009; Ahmad, 2011) pertaining to exercise and sports participation in the South Asian cohort has focused on the barriers towards active participation. For example, Koshoedo et al. (2015) investigated the barriers towards physical activity among Black and minority populations (BME) in the UK and conducted a qualitative synthesis to identify these barriers. Koshoedo et al. (2015) found fourteen papers (Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et al., 2000; SportScotland, 2001; Carroll et al., 2002; Rishbeth, 2004; Lawton et al., 2006; Openspace, 2006; Netto et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008; Jepson et al., 2008; Keval, 2009; Ahmad, 2011) that matched the inclusion criteria, with 10 out of the 14 studies (Williams & Sultan, 1997; Farooqi et al., 2000; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Sriskantharajah & Kai, 2007; Jepson et al., 2008; Keval, 2009; Ahmad, 2011) restricted to South Asians who were primarily Indian, Pakistani and Bangladeshi. Three of the 14 studies (Williams & Sultan, 1999; Carroll et al., 2002; Ahmad, 2011) focused solely on South Asian women's attitudes towards physical activity. The remaining four papers (Rai & Finch, 1997; SportScotland, 2001; Rishbeth, 2004; Openspace, 2006) included both Black and South Asian groups in their samples. In the majority of papers (Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et al., 2000; Carroll et al., 2002; Rishbeth, 2004; Netto et al., 2006; Sriskantharajah & Kai, 2007; Jepson et al., 2008; Keval, 2009; Ahmad, 2011), it was unclear which generations were included. Three studies (SportScotland, 2001; Lawton et al., 2006; Grace et al., 2008) restricted their samples to a mix of first

and second-generation South Asians.

The synthesis by Koshoedo et al. (2015) revealed four focal barriers to physical activity in Black and ethnic minority (BME) communities, which were shaped by four integral notions (p. 5): perceptions of physical activity; personal barriers; cultural expectations; and factors which limited access to facilities. The first of the four concepts related to perceptions and beliefs of BME communities towards physical activity (Koshoedo et al., 2015). Ten of the 14 papers (Rai & Finch, 1997; Farooqi et al., 2000; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Sriskantharajah and Kai, 2007; Grace et al., 2008; Jepson et al., 2008) reported that there were mixed views about physical activity among Black and ethnic minorities, and questioned
whether it was a formal or informal routine. In Netto et al.'s (2006) study, South Asian groups in particular, considered physical activity to be inappropriate, redundant and as something of no value to them. Instead, physical activity in these groups was believed to cause damage to the body rather than something with beneficial value (Netto et al., 2006). For example, physical activity was believed to be harmful to the body and as something which caused further weakness and disease (SportScotland, 2001; Netto et al., 2006). Additionally, individuals from South Asian groups, held the belief that physical activity did not play a preventative role in illness (Rai & Finch, 1997; Williams & Sultan, 1999; Lawton et al., 2006; Netto et al., 2006; Grace et al., 2008; Jepson et al., 2008). For those with an Islamic background, growing older was believed to cause illness and an external locus of control (such as, God) were considered influential in causing illness. This meant that physical activity played an insignificant role in helping to prevent illness (Lawton et al., 2006; Netto et al., 2006). Thus, some individuals did not take part in physical activity as a preventative measure to illness (Lawton et al., 2006; Netto et al., 2006).

According to four of the papers (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah & Kai, 2007; Jepson et al., 2008), South Asian respondents stated that physical activity was absent from their culture. In Rai & Finch's (1997) and SportScotland's (2001) investigations, both South Asian adults and African and Caribbean adults were included in the samples, though the African and Caribbean respondents did not report that physical activity was absent from their culture. It was mentioned however, that BME individuals including African and Caribbean adults and South Asian adults found it difficult to readily incorporate physical activity into their lifestyles (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah & Kai, 2007; Jepson et al., 2008). It was demonstrated that South Asian groups considered physical activity as something borne out of 'Western' culture and uncharacteristic of their

South Asian culture (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah & Kai, 2007; Jepson et al., 2008). The belief that physical activity was absent from South Asian culture was due to the limited childhood exposure to such activity when the respondents were young and lived in their country of origin. As a result, when they immigrated to the UK, physical activity was perceived to be a part of 'Western' culture, instead of South Asian culture (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah & Kai, 2007; Jepson et al., 2008). The lack of physically active or sporting role models from their minority ethnic groups, and the promotion of unhealthy lifestyles explained the lack of exposure in their birthplace or ancestral country (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah, & Kai, 2007; Jepson et al., 2008). It should be made clear that the evidence mentioned is between 11-22 years old, and the lack of sporting role models from BME communities is less relevant today.

One of the main personal barriers to physical activity was the increased emphasis placed on work commitments and working longer hours to financially support themselves in the UK, particularly after migration. This was reported in nine papers in Koshoedo et al.'s (2015) synthesis (Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et al., 2000; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008; Jepson et al., 2008). Low confidence and motivation were also common personal deterrents to participation, and there was no perceived enjoyment to take part because it was a separate activity from their lifestyles (Rai & Finch, 1997; Williams & Sultan, 1999; Netto et al., 2006; Jepson et al., 2008). Low levels of confidence were augmented by being in unfamiliar environments and having a lack of social networks (SportScotland, 2001; Rishbeth, 2004; Lawton et al., 2006). For first-generation migrants, the lack of knowledge about new services made physical activity difficult to integrate (SportScotland, 2001; Rishbeth, 2004; Lawton et al., 2006).

Other external barriers included the distance to sporting facilities (SportScotland, 2001; Lawton et al., 2006; Grace et al., 2008; Jepson et al., 2008; Keval, 2009), cost of such facilities (Rai & Finch, 1997; SportScotland, 2001; Carroll et al., 2002; Grace et al., 2008), and accessing these facilities in unfamiliar neighbourhoods (SportScotland, 2001; Lawton et al., 2006; Jepson et al., 2008). The lack of familiarity about their environments increased fear and uncertainty about safety. This was more prominent in women of South Asian and Black origin and it made it difficult for these groups to access sporting facilities (SportScotland, 2001; Lawton et al., 2006; Jepson et al., 2008). Koshoedo et al. (2015) noted that the external barriers mentioned are not specific to BME communities but that BME individuals, including South Asians, believed that both financial and time

expenditure on exercise was wasteful and low priority, as also reported in Lawton et al. (2006).

The third of the main concepts in Koshoedo et al.'s (2015) synthesis related to cultural and religious expectations, which acted as deterrents to physical activity participation (Williams & Sultan, 1999; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Jepson et al., 2008; Ahmad, 2011). SportScotland's (2001) and Lawton et al.'s (2006) investigations found that some South Asian individuals expected exercise and sporting facilities to include segregated facilities and same-sex instructors in accordance with their cultural and religious practices. These cultural expectations were more pronounced for people with an Islamic background, whose expectations stemmed from their religious practices of single-sex and segregated environments (SportScotland, 2001; Lawton et al., 2006). Although there are segregated facilities in the UK, some South Asian groups were unaware of their existence (SportScotland, 2001; Jepson et al., 2008). Other South Asian groups were unable to understand the information about physical activity because of language barriers, though, this was more noticeable in older groups and first-generation migrants (Farooqi et al., 2000; SportScotland, 2001; Carroll et al., 2002; Grace et al., 2008). Other deterrents included the time constraints from other cultural priorities, such as family obligations (Rai & Finch, 1997; SportScotland, 2001; Lawton et al., 2006; Jepson et al., 2008). According to Lawton et al. (2006), these deterrents affected South Asian women more than South Asian men because women have extensive cultural responsibilities and expectations placed on them after marriage (Lawton et al., 2006). This is explored in further detail in the following section (see section 2.3.2) which focuses on the interplay between South Asian culture, gender identity and barriers to physical activity participation.

2.3.2 Gender differences in sport and/or exercise participation: Cultural barriers for South Asian women

Following on from Koshoedo et al.'s (2015) qualitative synthesis of 14 studies, this section details barriers and deterrents to physical activity that are specific to South Asian women. In Koshoedo et al.'s (2015) review, many of the cultural expectations were more pronounced for South Asian women than men of the same community (Koshoedo et al., 2015). These cultural expectations included the maintenance of specific dress codes, such as loose-fitting clothing, restricted access of movement outside of the home, and gender-specific cultural obligations after marriage (Williams & Sultan, 1999; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Jepson et al., 2008, Ahmad, 2011). The desire to maintain a specific dress code was more pronounced for Muslim women, which often included wearing a hijab as well as loose-fitting clothes (Williams & Sultan, 1999; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Jepson et al., 2008, Ahmad, 2011). This was particularly pertinent for Muslim women (Ahmad, 2011; Koshoedo et al., 2015), who wear the hijab[5] as an act of Islamic faith (Furseth, 2014). Further, the wearing of the hijab represents, what Muslim women believe to be, the appropriate way to behave in society (Furseth, 2014; Benn, Jawad & Pfister, 2010). In Ahmad's (2011) study of British Muslim South Asian female footballers, there was a fear that acting outside of these cultural expectations broke the rules, which warranted condemnation from others of the same community (Ahmad, 2011). Sriskantharajah & Kai (2007) reported that South Asian women from all religions, were concerned about their appearance at public swimming pools. When they were required to wear a swimming costume, they cited feeling uncomfortable and were worried about how others would perceive them. Therefore, the threat of not abiding by these cultural expectations contributed to the lack of participation in physical activity for some South Asian women (Ahmad, 2011). Individuals from these groups found it difficult to adhere to cultural and religious expectations, whilst also becoming active sporting individuals (Ahmad, 2011). According to Koshoedo et al. (2015), some South Asian women were either required to, or wanted to adhere to their cultural expectations, which subsequently impacted their decision to engage in physical activity.

Additionally, engaging in physical activity was considered to be a reflection of selfishness for some

[5] A hijab is a veil worn by some Muslim women when they are in the presence of males who are not a part of their immediate family, for example, a male co-worker (Siraj, 2011). The hijab is used to cover the woman's head and chest and to reflect a modest appearance (Siraj, 2011).

South Asian women because it meant abandoning other responsibilities (Sriskantharajah & Kai, 2007). According to Sriskantharajah & Kai (2007), the women in their sample emphasised their role as homemakers, who engaged in daily activities, including cleaning the house, shopping for household items, cooking for their families, and looking after their children and other relatives. These activities were subsequently perceived as "*valued physical activity*" (p. 74). Koshoedo et al. (2015) argued that this is because the women's gender identity has been dictated by their cultural roles and responsibilities, as well as their familial obligations. For example, emphasis was placed on women to place familial responsibilities first before engaging in physical activity, and for them to attend to domestic chores and to remain indoors (SportScotland, 2001; Lawton et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008). Furthermore, some South Asian women were deterred from physical activity, due to the fear of racial and religious discrimination (SportScotland, 2001; Carroll et al., 2002; Netto et al., 2006; Grace et al., 2008; Jepson et al., 2008; Ahmad, 2011). In Ahmad's (2011) study, some South Asian Muslim women reported fears about safety, and avoided visiting facilities which they were unaccustomed with. Additionally, respondents described experiences of personal or institutional racism from different community groups (e.g., White population) and from others in the same community group. The potential for discriminatory behaviours from others increased when the South Asian woman's participation was questioned or condemned by their community (Ahmad, 2011). This was particularly pertinent in Ahmad's (2011) study, where participation in football by some South Asian women was castigated by others in the same communities as the women. Some South Asian women also felt discriminated against for wearing different types of sports clothes to the traditional formal sportswear worn by others in different ethnic groups (e.g., White population) (Jepson et al., 2008). Furthermore, among the Bangladeshi community, physical activity was believed to cause gossip and laughter among women of the same community (Grace et al., 2008).

Babakus and Thomspon (2012) completed a mixed-methods quantitative and qualitative synthesis of published studies regarding physical activity among South Asian women. Unlike Koshoedo et al.'s (2015) review, which was restricted to UK-based studies, Babakus and Thompson's (2012) synthesis included international literature, including papers from Canada, the UK, the United States (US), New Zealand, Australia/India in the same study, Guadeloupe and Norway. Babakus and Thompson's (2012) aim was to synthesise literature which compared the levels of physical activity between South Asian women and men of the same community and other general populations, such as the White population. There were 26 quantitative studies and 12 qualitative studies included in Babakus and

Thompson's (2012) review.

In Babakus and Thompson's (2012) quantitative synthesis, 15 studies were conducted in the UK, 6 in the US, 2 in Canada, 1 in New Zealand, 1 in Australia/India in the same study, and 1 in Guadeloupe. Three of the 26 studies were restricted to South Asian women. Within the included quantitative studies, the focus was targeted towards the measurement of physical activity and sedentary time. As previously mentioned in section 1.3, South Asians, especially South Asian women, are less likely to participate in physical activity, including sport and exercise than the White population. All of the studies that measured the prevalence of physical activity of South Asians, in comparison to the White or general population, found that South Asians participated in significantly less physical activity that the comparison group. In Misra, Endemadd and Ayer's (2005) study, which investigated the relationship between physical activity and metabolic syndrome in South Asian US Indian immigrants, it was found that South Asian men completed approximately 45 minutes of physical activity. Their female counterparts, however, performed an average of 16 minutes of physical activity (Misra et al., 2005). Although the quantitative synthesis has provided some insight into the levels of difference in activity, the studies did not investigate the reasons why some South Asian women did not take part in physical activity. However, Babakus and Thompson's (2012) qualitative synthesis focused on South Asians knowledge of physical activity, and the barriers to participation. Similarly, to Koshoedo et al.'s (2015) qualitative review, the majority of qualitative studies in Babakus and Thompson's (2012) synthesis revealed comparable cultural barriers to active participation. For example, in Mohan, Wilkes and Jackson's (2008) study, it was reported that some South Asian Indian Australians perceived familial obligations as higher priority than physical activity.

Although this evidence has provided well-informed explanations about why some female South Asian groups may not participate in physical activity, it attributed their reasons and attitudes towards orthodox South Asian attitudes and behaviours, including women being restricted from leaving the family home. Burton, Nandi and Platt (2008) explained that much of the early research has fixated on stereotypes such as *"…Asian's don't like sport"* (p. 25) and criticised this evidence for being stereotypical and ethnocentric. Andersson's (2002) Norwegian study, for example, investigated how Norwegian-Pakistani girls wanted to change what it meant to be a Pakistani woman through sport involvement and to become sporting role models for other Pakistani girls. By challenging traditional gender identities through sport involvement, Andersson (2002) explained that her respondents disputed the shared stereotypes of the South Asian minority in present-day Norwegian society. In Ahmad's (2011) study of female South Asian footballers, it was reported that

the hijab acted as a barrier to sport involvement in the UK where football organisations are perceived not to embrace the hijab, as evidenced by the FIFA ban of the hijab in 2007[6] (Ahmed, 2018). According to Ahmad (2011), her respondents challenged traditional cultural ideals when they competed in the international Women's Islamic Games in Iran whilst wearing the hijab. Ahmad (2011) explained that the games allowed them to express their religious identities where the hijab was not considered a barrier and without feeling that their religious or cultural identities were under threat. Consequently, the women were able to hold onto their identity as Muslims and negotiate the traditional cultural ideals of femininity whilst being active sporting individuals. Both studies (Andersson, 2002; Ahmad, 2011) have also demonstrated that some South Asian women are motivated to engage in sport. The following section (see section 2.3.3) discusses the handful of evidence which has explored in-depth what motivates South Asians to take part in physical activity, sport and exercise.

2.3.3 Motivations and facilitators for sport and exercise participation for South Asian adults

In three of the studies mentioned previously (e.g., Lawton et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008) (see sections 2.3.1-2.3.2), facilitators to physical activity emerged, though, in less detail than barriers to active participation. For example, there was motivation to engage in physical activity to take care of the health of the body and alleviate illness (Sriskantharajah & Kai, 2007; Grace et al., 2008). Physical activity was also related to religious identity for Bangladeshi Muslim women, who reported that an active lifestyle was central to the Muslim way of life (Grace et al., 2008).

A recent study by Jepson et al. (2012), who explored the motivations and facilitators of physical activity in South Asian groups living in Scotland, reported that the main motivators for participating in physical activity, included the enjoyment of taking part, losing weight, and improving mental and physical health and wellbeing. Role models were perceived as important to motivate and increase uptake of participation. As previously mentioned in section 2.3.1, the lack of role models was used to explain the lack of engagement in some South Asian groups (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah, & Kai, 2007; Jepson et al., 2008). A recent study by King and Little (2017) investigated South Asian users' experiences of a community gym in West Yorkshire in the UK. Unlike some of the studies explored in section 2.3.1 (e.g, Rai & Finch, 1997; Williams & Sultan, 1999; Netto

[6] The hijab ban was imposed by FIFA and was lifted in 2012, after the FIFA medical committee tested athletic hijab prototypes for women to wear during football (Ahmed, 2018).

et al., 2006; Jepson et al., 2008), King and Little (2017) reported that most of the South Asians they interviewed were clearly aware of the health benefits of regular exercise.

There was also some awareness of longer-term preventative health benefits of active participation (King & Little, 2017). Similar to Jepson et al. (2012), King and Little's (2017) South Asian respondents engaged in regular exercise to improve their psychological wellbeing. Additionally, the gym in question, catered for respondents' cultural expectations, for example, there were single-sex sessions available (King & Little, 2017). However, none of the users suggested that cultural expectations were of greater importance than their participation at the gym (King & Little, 2017). Thus, King and Little (2017) acknowledged the distinctiveness of South Asian groups yet stated that investigations regarding South Asian groups should be cautious not to overemphasise how specific South Asian communities differ from other populations, such as the White population.

Jepson et al.'s (2012) and King and Little's (2017) studies demonstrated that some South Asian groups view participation in regular exercise and physical activity positively. King and Little's (2017) research, however, only focused on those who attended a gym, and the research did not show that involvement in the gym motivated respondents to participate in activities outside of the gym, such as sport participation. In both studies (Jepson et al., 2012; King & Little, 2017), respondents did not indicate that they had any type of chronic illness, such as asthma, which is suggestive that there is gap in the literature pertaining to the experiences of exercise and sport participation in South Asian adults with asthma; the focus of the current research.

2.4 Limitations of previous research

The evidence has demonstrated that one of the main goals in asthma research has been towards improving treatment adherence and self-management behaviours in South Asian groups with asthma (Griffiths et al., 2001; Hussein & Partridge, 2002; Lakhanpaul et al., 2014; Lakhanpaul et al., 2016). Whilst the empirical data examined in this chapter provides a useful context in which to situate this thesis, this overview has identified a number of limitations and significant gaps in what is currently known about sport and exercise behaviour in UK-resident South Asian groups with asthma.

The majority of evidence has focused on childhood populations and the parent's perspective of asthma (Lakhanpaul et al., 2014; Lakhanpaul et al., 2016). This is because there is an emphasis to improve self-management behaviours in younger Asian groups, who are at increased risk of accident and emergency (A&E) hospital admissions (Lakhanpaul et al., 2014). This has contributed to the

limited evidence available on UK adult South Asian populations. The two exceptions to this (Griffiths et al., 2001; Hussein & Partridge, 2002) also have limitations. As mentioned previously (see section 2.2.5), Hussein and Partridge's (2002) and Griffiths et al.'s (2001) findings are between 17-18 years old and investigated South Asian groups that were originally from India, Pakistan, Bangladesh or Sri Lanka. Hussein and Partridge's (2002) study was restricted to an Indian and Pakistani sample. Neither study included South Asians who were born in the UK, nor did the studies explore sport and exercise in their investigations, though, Hussein and Partridge (2002) mentioned sport and exercise from one respondent. Other studies about asthma have been based in other countries, such as India or Pakistan, where the socioeconomic status and education level is different to that of the UK. For example, in Banga et al.'s (2017) study, the sample included mothers who were illiterate, and this may have influenced their educational awareness of asthma.

Similarly, one of the primary goals in sports and exercise related research is to improve levels of participation in majority and minority populations (Jepson et al., 2012), and has focused on the barriers (Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et al., 2000; SportScotland, 2001; Carroll et al., 2002; Rishbeth, 2004; Lawton et al., 2006; Openspace, 2006; Netto et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008; Jepson et al., 2008; Keval, 2009; Ahmad, 2011) and motivators to sport and exercise (Jepson et al., 2012; King & Little, 2017) engagement in South Asian groups. However, none of the studies which focused on sport and exercise included respondents with asthma. Instead, the evidence was either based on South Asian groups without any reported illness (Rai & Finch, 1997; SportScotland, 2001; Carroll et al., 2002; Rishbeth, 2004; Openspace, 2006; Jepson et al., 2008; Ahmad, 2011) or included those with diabetes (Lawton et al., 2006; Grace et al., 2008; Keval, 2009), coronary heart disease (Farooqi et al., 2000; Netto et al., 2006; Sriskantharajah & Kai, 2007) or obesity (Williams & Sultan, 1999).

The overview of literature has therefore demonstrated that there is a lack of literature investigating the combination of asthma, sport and exercise in a UK-resident South Asian adult population with asthma, who were born in the UK or migrated here at an early age. This dearth of evidence can also be linked to the difficulty of collecting data on asthma because of the reported social stigma attached to South Asians with asthma (as reported in Smeeton et al., 2007; Lakhanpaul et al., 2014). Rooney et al. (2011) also commented on this and explained that UK-resident South Asians are sometimes fearful of taking part in asthma research because of the perceived stigma attached to the condition, further limiting opportunities to research this subject. A shift in focus towards understanding individual reflections and exploring the lived experiences of exercise and sports in UK-resident adults with

asthma is likely to enhance understanding about asthma, sports and exercise behaviour in the South Asian population.

This chapter aimed to orientate the reader to salient research and debates relating to South Asian groups perspectives of asthma and sport and exercise. It has provided a comprehensive review of the current literature and highlighted existing gaps in the current knowledge base. The following chapter contextualises the current study within additional conceptual debates to create the context in which the current study has been grounded.

Chapter Three: Conceptual frameworks

3.1 Introduction

This chapter explains how symbolic interactionism is used in combination with a phenomenologically-inspired approach in the thesis. The work of Goffman's (1959) presentation of self, Goffman's (1969) discussion of stigma, and Leder's (1990) and Zeiler's (2010) embodied phenomenological approach to the lived body, are drawn upon to analyse the accounts of South Asian adults with asthma and their sporting and/or exercising experiences.

3.2 Symbolic interactionism

Symbolic interactionism (SI) is a micro level theoretical framework. It proposes that society is shaped and upheld by social interaction between people (Carter & Fuller, 2015). The SI approach was largely influenced by the American philosopher, George Herbert Mead (1934), who theorised about the relationship between the self and society, which remain seminal to the current day. According to Carter and Fuller (2015), SI was developed in order to understand how society is maintained in relation to the micro-level processes involved, where the focus remains with the individual and their interactions with others. From the SI perspective, the individual is considered as agentic and integral in creating their social world (Carter & Fuller, 2015).

Central to the SI approach is the idea that individuals use language and symbols to influence their behaviour when they interact with others (Carter & Fuller, 2015). Thus, symbolic interactionists explore how people make sense of their social world from their own perspective (Carter & Fuller, 2015). In the current research, the SI approach was used to understand how South Asian adults with asthma make sense of their condition and their exercising and/or sporting experiences. The four basic tenets of SI are explained by Blumer (1969): i) individuals act towards things (including other individuals) based on the meanings these objects have for them; ii) social interactions occur within a particular social and cultural context; iii) the individual creates meaning during social interactions; iv) meaning is continuously created and recreated through interpretive actions during social interactions with others.

Mead (1934) considered the self and mind in terms of social processes and as the 'I' and the 'me' (Silva, 2013). The 'me' is the socialised aspect of the person, the social self, and is characterised by the behaviours, attitudes and expectations of others in society (Silva, 2013). The 'me' is the

structured set of attitudes of others and has social interactions with others in society, thus developing knowledge about society and the 'generalised other' (Mead, 1934). The 'I', or the self as subject, is the present and is the response to the attitudes of others and to the 'me' (Silva, 2013). An individual establishes a personal identity when they see that they exist as the 'I' or the 'self as subject' (Silva, 2013). This is often referred to as the 'existential self' (Silva, 2013). Mead (1934) believed that an individual's thinking process, or the 'stream of thought', is the internalised dialogue and the interaction between the 'I' and 'me' (Silva, 2013). Thus, for Mead (1934), the self's 'perception and meaning' in social interactions with others intertwined with sociological existence and argued that existence in community comes before individual consciousness (Silva, 2013). For example, before an individual becomes self-conscious, they must first engage in various social positions and use that experience to assume the perspectives of others (Silva, 2013). Another step in the development of a full sense of self is termed the 'me', or the 'self as object' (Silva, 2013). This is known as the 'categorical self' which focuses on the abilities or the characteristics that individuals have, in order to attain a certain level of self-awareness (of the 'existential self') (Silva, 2013). This is also thought to be heavily influenced by social factors (Silva, 2013).

In the context of the current research, a symbolic interactionist (SI) framework was appropriate. Having asthma can influence the individual to consider the choices he/she makes with regard to their healthcare. In SI terms, individuals' make choices dependent on the social context and their social encounters with other people. Here, Mead's (1934) conceptualisation of the 'I' and 'Me' are in effect. The 'I', or the subjective component of the self might want to make spontaneous decisions. The 'me', or the objective component of the self, compensates the 'I' by making decisions which have been socially constructed.

For Mead (1934), individuals are considered social actors. According to Mead (1934), interaction between individuals is governed by the social actors' interpretation of the interaction (Silva, 2013). Social actors respond, rather than simply react, dependant on the meaning they attach to a situation or action (Silva, 2013). The following ideas are integral to Mead's (1934) theorisation of the SI approach; i) it is about the micro-level analysis of social interactions between the social actor, other individuals and the world, ii) the social actors' perspective, as well as the world's perspective are considered dynamic and fluid processes instead of fixed structures and finally; iii) social actors' are skilled at interpreting their reality. Silva (2013) added that the SI approach lays emphasis on symbolic structures and meaning because it is essential to the construction of the social world and influences

the roles people adopt and play in their world. In the current research, it was about how people adopt an asthmatic role and a sporting role, and how they interacted with others including healthcare professionals and other sporting peers.

Identity, from the SI perspective, has become a way to reconceptualise the concept of 'self'. The idea of 'self' is now considered to be a set of identities, which are either invoked individually or simultaneously in different situations. When these identities are evoked, he/she acts in an appropriate manner, where their identities can be verified by their audiences. Thus, according to the SI theory, people aim to verify their sense of self in front of others (Turner, 2013). With individuals mutually performing different roles, a more refined theory of self was proposed by Goffman (1959; 1963).

Goffman (1959) was a mainstream advocate for studying the roles people play in society. Although Goffman (1959) argued that he was not a symbolic interactionist, he considered the importance of symbols and gestures during social interactions. Symbols such as, appearance and manner, for example, are considered important for social roles and for understanding how to behave. Goffman (1959) explained that humans are role-playing actors, who follow formulated scripts and it is one of the key theoretical perspectives pertinent to the overarching context of the current research. Goffman's (1959) insights fit with the SI perspective, which perceives social life as a function of interactions between individuals (or social actors) in different contexts, and which emphasises the meaning of symbols, such as, language, gestures and appearance, and how these symbols shape or mould people's interpretations of the world and of others in it (Carter & Fuller, 2015).

Goffman (1959) argued that the word 'person' was derived from the term 'persona', which related to the masks worn by characters in Greek tragedies. Thus, *"…to be a person is to be a mask, to play a role"* (Lawler, 2015, p. 120). In her book about 'Identity: Sociological Perspectives – Masquerading as ourselves: Self-Impersonation and Social Life', Stephanie Lawler reviewed Goffman's (1959) ideas, and explained that for Goffman (1959), *"…to be a person is to perform being a person"* (Lawler, 2016, p. 121). Goffman (1959) quoted Parks (1950):

> *"In a sense, and in so far as this mask represents the conception that we have formed ourselves – the role we are striving to live up to – this mask is our truer self, the self we would like to be. In the end, our conception of our role becomes second nature and an integral part of our personality. We come into this world as individuals, achieve character, and become persons"* (Parks, 1950, p. 250, as quoted in Goffman (1990, p. 30).

Goffman (1959) argued that we are not only performing different roles, but that our roles and performances are what make us 'persons'. As people, we are constantly aware of others and want others to recognise what we are doing, this is known as 'dramatic realisation'. This demonstrates the significance of the social group in Goffman's (1959) insights, who stated that we act out for their benefit. According to Lawler (2015), Goffman (1959) suggested that we pay less attention to authentic and inauthentic performances, and instead focus on what creates a convincing and/or unconvincing performance, or between those that 'work' and those that do not. Goffman (1959) was not arguing that we are consciously trying to manipulate one another, instead, he believed that social life is artificial and that we bracket off some aspects as 'true' or 'real' and some as 'untrue' or 'unreal'. Thus, the performing of an identity is an unavoidable process, and that we could not be part of the social world without it. The self does not cause a social situation, rather, it is the product of social situations. As Goffman (1959, p. 245) quoted:

> *"…the self, then, as a performed character,… is a dramatic effect arising diffusely from a scene that is presented, and the characteristic issue is whether it will be credited or discredited".*

Therefore, social identity and social reality are products of performance. The following section considers Goffman's (1959) theoretical insights on self-presentation in more detail.

3.3 Self-presentation

Goffman's (1959) dramaturgical analysis expands on the ideas of Charles Cooley (1902) and the looking-glass self. Cooley (1902) argued that a person's self-concept was influenced by the views of others or the 'looking-glass self'. According to Cooley (1902), social interaction is used as a 'mirror', where others' perceptions exert a powerful influence on an individual's conceptions of him/herself. These perceptions are then used to influence how he/she behaves with others. Cooley's (1902) theoretical insight has three core assumptions; an individual involved in social interaction imagines how he/she is being perceived by others; the individual deliberates about the others' judgements; and lastly, the individual responds to these perceived judgements. Goffman (1959; 1963) was also influenced by Mead's (1934) insights and argued that identity is negotiated, not by how a person identifies themselves, but how others identify them; it is about how one presents aspects of the self to others, or self-presentation. Self-presentation refers to behaviour that attempts to show or present information about oneself, or an image of oneself to others (Baumeister & Hutton, 1987, as cited in Mullen & Goethals, 1987). It involves being in a 'performance' and behaving in ways that create an

impression, which is desired by the audience (Goffman, 1959). Performance is referred to as *"…all the activity of an individual which occurs during a period marked by his presence and which has some influence on the observers"* (Goffman, 1959, p. 32). Thus, social meanings related to bodily displays are significant features of an individual's sense of self (Goffman, 1959). According to the Goffman (1961), a crucial task is to maintain the definition of the situation during social interaction. The 'definition of the situation' is the agreed upon subjective understanding of what is expected within a given situation, and the agreed upon roles each person plays in the interaction (Jacobsen, 2010). It is about how people understand the social context of their interactions, and through the definition of the situation, he/she understands the roles of those involved, and understands how to behave appropriately.

Through the metaphor of dramaturgy, Goffman (1959) viewed everyday social interactions as a continuous series of staged exchanges. Dramaturgy is a psycho-sociological perspective adapted by Goffman (1959) and is used in small-scale analysis or micro-level accounts of social interaction, such as face-to-face interaction. In dramaturgical analysis, social interactions depend on the time, place and audience. In essence, Goffman (1959) argued that the self emerges from the scene being presented at the time. Self-presentation is understood as presenting a particular 'self' to an audience in a performance (Goffman, 1959).

Self-presentation is part of a wider group of behaviours, known as impression management. Impression management refers to the techniques used to control the presentation of information about oneself to the audience (Goffman, 1959). According to Goffman (1959), actors use impression management techniques to perform in a way which enables them to fit the prerequisites of a specific context. Actors use specific techniques to avoid being embarrassed and to maintain the micro social order (Goffman, 1963). Thus, for Goffman (1963), interactions are cherished by social actors as they provide a social sense of belonging. To disrupt the interaction is to disrupt the social order in society (Goffman, 1963).

Although they did not directly apply Goffman's (1959) theorisation of presentation of self in their study, Adams, Pill and Jones (1997) provided an example of how White Caucasian adults with asthma self-present. The purpose of Adams et al.'s (1997) study was to understand how their sample of White Caucasian adults with asthma constructed their asthma identity and how they presented their asthma self to others. Adams et al. (1997) identified a tripartite typology; deniers/ distancers, accepters; and pragmatists. Adams et al. (1997) characterised those who willingly incorporated asthma into their social identity and as a part of their 'self' as 'accepters'. Deniers, on the other hand, perceived that

they did not have asthma, and distancers were characterised as those who admitted at times that they had "*slight*" asthma or "*not proper*" asthma (Adams et al., 1997, p. 192). When asked what "*proper*" asthma constituted of, respondents constructed a negative self-image of someone who was weak and could barely walk (Adams et al., 1997). This enabled them to reject or distance themselves from the social identity of an 'asthmatic', since they did not present this type of image to others (Adams et al., 1997). Since their symptoms did not always persist, deniers/distancers perceived their condition as acute condition, instead of a long-term chronic illness (Adams et al., 1997). It is possible that this was only when they were asymptomatic, though, Adams et al. (1997) did not clarify this.

In the denier/distancer group, it was evident that symptoms of asthma affected their everyday lives. They developed strategies such as, avoiding situations which would trigger their symptoms, in order to cope with their condition (Adams et al., 1997). Avoidance strategies enabled the distancers/ deniers to present as someone without 'proper' asthma, or as someone without asthma altogether. There were also differences in denier/distancers strategies of self-presentation, patterns of disclosure and use of preventer medication. For example, deniers/ distancers engaged in strict strategies of information control and developed ways to conceal their condition in public. For example, they took their reliever inhaler before it was necessary and used it frequently in closed spaces or out of view from others (Adams et al., 1997). This was mainly due to wanting privacy and the fear of embarrassment (Adams et al., 1997). Furthermore, Adams et al. (1997) explained that these strategies were in place because deniers/distancers wanted to present as people who led a normal life. In this way, they disassociated themselves from the role of an 'asthmatic' and the behaviours associated with it (Adams et al., 1997). Goffman (1961, p. 63) proposed that such detachment establishes *"…a wedge between the individual and his role, between doing and being"* and is expected to result in identity confusion or a "*diminished identity*".

Accepters on the other hand, accepted the necessity of both preventer and reliever medication (Adams et al., 1997). However, respondents in this group were equally as concerned with deniers/ distancers to lead a normal life. The difference was that accepters coped by taking their medication regularly, rather than avoiding it or denying that they needed medication (Adams et al., 1997). The accepters improved their sense of self-esteem when they compared themselves against other asthmatics who could not manage their condition well (Adams et al., 1997). Similarly, to deniers/distancers, the accepters viewed someone with asthma as 'weak' and 'decrepit', however, they re-interpreted what being asthmatic meant. Accepters drew upon role models who had coped with asthma such as, successful athletes (Adams et al., 1997). Accepters believed that they were not

ill because of asthma, instead, asthma was not considered to be an illness because it was manageable (Adams et al., 1997). Thus, their interpretation of asthma was re-defined, with many describing asthma as a 'condition', rather than an illness (Adams et al., 1997). The accepters did not conceal or deny their condition to others (Adams et al., 1997). Instead, they practised a strategy of full disclosure; to conceal their asthma would have been to constantly hide what already was an accepted part of their identity (Adams et al., 1997). Also, choosing to use their reliever inhaler in public spaces was unproblematic for respondents in this group; any negative suspicions from others were linked to the ignorance of those concerned (Adams et al., 1997). This was so that they could illustrate that their identity as an 'asthmatic' did not affect them in a meaningful way (Adams et al., 1997). Thus, their strategies of disclosure and presentation were related to the acceptance of their 'asthmatic' identity.

The third group, who were termed as 'pragmatists', were acknowledged as a potential subset of the accepter category, who did not reject the social identity of 'asthmatic' but were more concerned than the accepters about disclosure (Adams et al., 1997). According to Adams et al. (1997), the pragmatists were similar to the deniers/distancers because they did not take their prophylactic medication (at least according to their prescribed regimen), but unlike the deniers/distancers, pragmatists accepted that they had asthma. Although they accepted their identity as asthmatics, some respondents claimed that their asthma was "*proper asthma*" but of the "*acute type, rather than the chronic type*" and protested the use of regular medication, arguing that this was unnecessary for their "*acute type*" of asthma (Adams et al., 1997, p. 10).

Adams et al. (1997) argued that identity was the most appropriate framework to investigate people's experiences of asthma, and how people either accept the identity or distance themselves from the label. Despite this recommendation, there has been a lack of follow up inquiry, particularly in minority populations including South Asian groups. Adams et al.'s (1997) study was limited to an investigation into the White Caucasian asthmatic population, and thus, did not consider an asthmatic individual's cultural identity, and how this affected medication adherence. Additionally, Adams et al. (1997) did not consider how respondents behaved in sporting contexts. Unlike Adams et al. (1997), the current research utilised Goffman's (1959) concept of self-presentation to achieve this understanding. Goffman's (1959) theorisation of the presentation of self is described in detail below.

When an actor performs, Goffman (1959) argued that he/she either performs on the 'front stage', or 'back stage'. The 'front stage' is described as:

> "*…that part of the individual's [or team's] performance which regularly functions in a general and fixed fashion to define the situation for those who observe the performance*" (1959, p. 22).

The 'front stage' provides the audience with information in the form of familiar and accustomed behaviours, appearances and settings, by observing certain rules and social conventions (Goffman, 1959). If the person fails to do this, it means they will lose face (Goffman, 1959) and will fail to project the image they wish to show to others (Goffman, 1959).

Therefore, the quality of an actor's performances is essential to his/her sense of self. In contrast, the 'back stage' is a setting *"…where the impression fostered by the performance is knowingly contradicted"* (Goffman, 1959, pp. 112–113). The actor's behaviour can be different in a 'back stage region', where there might be a different audience (Bullingham & Vasconcelos, 2013). Goffman (1959) argued that front region performances are formal and controlled, whereas back region performances are informal, and allow the individual to "…*relax…and step out of [their front region] character*" (p. 115).

When an actor performs on a 'front stage' or 'back stage' region, there are props in both settings (Goffman, 1959). The audience watch the actor who then responds to the audience's reactions (Goffman, 1959). According to Goffman (1959), one can use material objects to convey positive impressions, together with the way he/she speaks, moves, and dresses; all convey symbolic information about the individual to the audience. For example, this can include information about a person's gender, religion, or ethnicity.

Goffman (1959) utilised terminology, including 'performance', 'performer', 'audience', 'front and back stage' and 'setting', to catalogue specific characteristics of an individual's self-presentation. A performance is in essence, the creation, presentation or affirmation of an identity (real or assumed) through action (Jacobsen, 2010) and with his theorisations about self-presentation, Goffman (1959) clarified the complexities of social interaction (Hare & Goffman, 1988). Thus, a person's presentation of self is constantly negotiated and adapted to the situationally specific expectations, based on cultural values, norms and beliefs, and is shaped by the audience (Jacobsen, 2010). According to Jacobsen (2010), self-presentation can be influenced by cultural differences, for example, different cultures can have different ideas about how one should act.

According to Spencer-Oatey and Franklin (2012), culture is reflected in people's lives. An individual, or an actor in Goffman's terms (1959), can be influenced by their culture's customs, attitudes,

behaviours, values and languages (Spencer-Oatey & Franklin, 2012). This can help him/her to interpret his or her own behaviour and others' behaviour (Jiang, De Bruijn & De Angeli, 2009). Thus, culture can influence how one presents themselves to others (Jiang et al., 2009). In the current research, participants are situated within two different cultures; British and South Asian. For the current research's purpose, a consideration of British and South Asian cultures provided a better understanding of the participants' behaviour as actors. Examples of culturally influenced attitudes (as discussed in sections 2.3.1-2.3.3) relate to sport and exercise behaviour, where South Asian women were reported as being less likely to participate in sporting activity because it was perceived by others as immodest or culturally inappropriate (Grace et al., 2008; Ahmad, 2011). When an actor projects something that can threaten or discredit his/her identity, this can lead to a 'spoiled identity' (Goffman, 1963). In turn, the actor might feel embarrassed about their performance of self (Goffman, 1959). The concept of stigma and the 'spoiled identity' (Goffman, 1963) is discussed below.

3.4 Stigma

A 'spoiled' identity is defined as the *"…exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group"* (Scambler, 2009, p. 441). Goffman (1963) differentiated between two types of stigma; the discredited and the discreditable. Those whose stigma is apparent to others in social interactions are known as discredited (Goffman, 1963). For people with asthma, this would mean when their symptoms are displayed to others. On the other hand, the discreditable include those who believe that their stigmatising attributes are not immediately evident to the audience (Goffman, 1963). Since asthma is not apparent all of the time to others, particularly when symptoms do not show, it can be considered a discreditable feature of one's identity. When asthma is not immediately visible to the audience, the person with asthma can 'pass as normal' (Goffman, 1963), or as someone with a non-asthmatic identity. However, when their symptoms appear and the audience sees this, they become discredited and their identity can become 'spoiled' (Goffman, 1963). This is when they can no longer 'pass as normal' (Goffman, 1963).

'Passing' is a social interaction management strategy and involves *"…the management of undisclosed discrediting information about self"* (Goffman, 1963, p. 42). Goffman's (1963) conceptualisation of 'passing' is based on the notion that an individual has a personally stigmatising feature about self and requires information about this stigmatising feature to remain undisclosed in social interactions. It is the kind of information that marks someone as different, and in others' minds, changes them from

someone who is normal, to someone who is "…*tainted, or discounted*" (Goffman, 1963, p. 42). Goffman (1963) argued that people who have discreditable attribute(s) are at risk of being stigmatised, and thus, engage in 'passing' to decrease the risk of stigmatisation. This is:

> "…*because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent"* (1963, p. 74).

According to Goffman (1963), when one tries to conceal their spoiled identity, it is known as "*passing for normal*" (p. 87). Passing is about information control:

> "…*to tell or not to tell, to let on or not to let on, to lie or not to lie, and in each case, to whom, when and where"* (Goffman, 1963, p. 87).

In this way, the 'discreditable' person focuses on managing his/her identity by either revealing or concealing information related to the stigmatising feature (Goffman, 1963).

Goffman (1959, p. 57) considered metaphors in his work such as 'the mask', which is used as a form of deception in daily interaction. A 'mask' can be withheld information about oneself. It also enables the actor to bring forth particular aspects about his/herself in the interaction, whilst ostracising others (Goffman, 1963). The actor is not becoming someone else here, instead the mask and the hidden person behind it are features of the same individual (Goffman, 1959). According to Goffman (1959), an actor can distance him/herself from the expected character or role he/she is performing. This is known as 'role-distance'; the act of presenting oneself as being removed from or detached from the role he/she is being required to perform (Goffman, 1959). One of Goffman's (1959) most fundamental arguments was related to the expressions that people both give and give off. The former is about how actors create impressions that are expected to be communicated, for example, how they want or are expected to be seen by others, and the latter refers to impressions that are unintentional and are nonetheless seen by their audience (Goffman, 1955; Bullingham & Vasconcelos, 2013). An example of this unintentional act is when someone experiences an unexpected asthma attack in front of others, which can result in stigma.

In Goffman's (1963) terms, discrediting attributes such as having asthma, do not meet societal standards of 'normal' behaviour. As such, the actor is considered to be 'deviant' or undesirable and can be rejected by mainstream society (Goffman, 1963). They can have a 'spoiled' identity (Goffman, 1963). According to Goffman (1963, p. 14), there are three types of stigma; i) physical abnormality of

the body, which is the case in the current research when asthma symptoms are displayed to others; ii) personality or character traits and iii) stigma relating to a group who belong to a less desirable social group.

In essence, stigma is a social process where the reaction of the audience 'spoils' the actor's 'normal' identity, therefore labelling him/her as deviant (Goffman, 1963). For example, as discussed in section 2.2.3, for some South Asians, having asthma is stigmatised in their communities (e.g., Lal et al., 1995; Cane et al., 2001; Hazir et al., 2002; Singh et al., 2002; Vishra, 2004; Shivbalan et al. 2005; Smeeton et al., 2007) and in Goffman's (1963) terms, it can be perceived as discreditable and an undesirable trait to have for South Asians. The South Asian person with asthma, then, has a 'spoiled identity'. In Singh et al.'s (2002) study (see section 2.2.2), it was reported that only 7% of Indian women accepted the use of an inhaler, suggesting that the representation of an inhaler can be stigmatising for some groups. In cases where the person could be stigmatised, Goffman (1963) explained the actor can hide, or conceal aspects of the discrediting attribute and correct his/her behaviour by dedicating private effort (in the 'back regions'). The actor can learn how to master this behaviour, so as to not disrupt their subsequent interactions with others and reduce the risk of stigmatisation (Goffman, 1963). For example, if South Asian adults are at risk of being stigmatised for using their inhaler in front of other South Asians, they might take their inhalers out of sight (in the 'back regions'). When they use their inhalers out of sight, their inhaler is concealed from those who might stigmatise them. This, in turn, can lessen the prospect of a spoiled identity and improves subsequent social interactions.

To summarise, Erving Goffman's (1959) dramaturgical analysis has challenged how identity is formed and negotiated. By conceptualising face to face encounters in terms of theoretical performances, Goffman (1959) demonstrated how presentations of the self can be noticeable by pretence in some cases, which can be simultaneously habitual and intentional. When actors engage in daily interaction, they create performances and self-images which conceal undesirable aspects, whilst trying to emphasise positive features of the self, which are adapted to the specific audience and context. The self is *"…situationally defined"* (Elliott, 2014, p. 44) and identity emerges from the roles performed and the self that experiences them. In this way, Goffman (1959) argued that identity is the effect of particular social interactions, in contrast to the notion that identity is innate and formed prior to social experience.

Further, Goffman (1959) argued that bodily presentation facilitates the connection between self-identity and social identity. Subsequently, the meanings attached to bodily presentation or the

presentation of the body in front of others, can be deemed significant for an individual's sense of self (Goffman, 1963). For example, if a person with asthma is stigmatised by their audience for displaying symptoms of asthma, this might negatively impact their sense of self. The following section (see section 3.5) describes how the consideration of the body is pertinent to social interaction by drawing on phenomenologically-inspired approaches which study the body and argue that the body be brought "…*back in*" (Allen-Collinson, 2009, p. 279) to the investigation of lived experience. In the current research, this applied to the study of the asthma and sporting body. Thus, the next section (see section 3.5) considers some of the phenomenologically-oriented work considered relevant to the analysis of the lived experience of asthma amongst sporting individuals in the South Asian population.

3.5 Phenomenologically-inspired theories

Martínková and Parry (2011) proposed that a theoretical perspective informed by a phenomenologically-inspired understanding can provide a broader, more holistic interpretation of movement by the body, particularly in the study of sport. Currently, there remains a paucity of literature in the area of asthma and sport and exercise in all populations using a phenomenologically-inspired approach (with the exception of Owton, 2012; Allen-Collinson & Owton, 2014; Allen-Collinson, Owton & Crust, 2016; Owton & Allen-Collinson, 2016) and what exists is from a small number of writers on the topic.

For example, Allen-Collinson and Owton (2014) sought to understand sporting embodiment via a phenomenologically-inspired sociological lens and investigated how non-elite sportspeople with asthma make sense of their senses, or their 'somatic work', and focused on the aural features, or 'aural attunement' and 'auditory work' of asthma experiences. Further work by Allen-Collinson, Owton and Crust (2016) explored the experiences of asthma and sport and/or exercise using vignettes and considered how these could be used to help people reflect on their experiences with asthma and ways of being-in the-world. Allen-Collinson et al. (2016) argued that acknowledging a person's embodied experience of asthma, and their somatic ways of knowing and combining this with specialised healthcare knowledge about sport and/or exercise, can stimulate behaviour change and can be greatly beneficial to those with asthma and healthcare professionals. Other work, including Owton and Allen-Collinson's (2014) research stemmed from Owton's (2012) thesis on the lived experiences of asthma and sporting embodiment. In her thesis, Owton (2012) examined how sportspeople with asthma in the White Caucasian population experienced their condition, using a phenomenologically-inspired approach. Owton (2012) explored asthma sporting embodiment and developed a threefold asthma

identity typology by drawing upon Arthur Frank's (1993, 1995) phenomenologically-inspired conceptual insights to develop her typology. Frank (1995) argued that:

> *"…people who tell their stories are not simply seeking to describe their sick bodies, but that their bodies give their stories particular shape and direction…"* (p. 27).

Frank's (1995) insights emphasise body problems. He proposed four problems of embodiment: control; body-relatedness; other-relatedness; and desire, and each is a problem of action (Frank, 1995). Frank (1995) stated that each body-self must be able to respond and resolve each body problem and he provided a variety of conceivable responses for this via four ideal body types: the disciplined body; the mirroring body; the dominating body; and the communicative body (Frank, 1995, p. 30). He also developed three basic narrative types to help describe an illness story; restitution, chaos and quest (Frank, 1995). Using Frank's (1995) insights, Owton (2012) developed a typology of sporting asthma identities based on three ideal types: conformers; contesters; and creators. Commensurate with a phenomenologically-inspired perspective, and with Frank's (1995) work, Owton and Allen-Collinson (2014, p. 10) emphasised the fluidity and context-dependency of these ideal types.

Owton (2012) and Owton and Allen Collinson (2014) explained that conformers were more likely to describe that they were actively managing asthma by complying to prescribed treatment regimens and accepted their diagnosis, similar to the behaviours of 'accepters' in Adams et al.'s (1997) study. According to Owton (2012) and Owton and Allen-Collinson (2014), conformers adopted Frank's (1995) restitution narrative which is, "…*yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again…"* (p. 77). Owton and Allen Collinson (2014) explained that this was conceptualised differently for sportspeople with asthma as, *"…a moment ago I could breathe, now I'm having difficulty, but in a moment, I'll be able to breathe again…"* (p. 11). Conformers wanted to restore their state of health and often resorted to their inhaler, which worked quickly in reducing symptoms such as laboured breathing (Owton & Allen Collinson, 2014), matching Frank's (1995) concept of the disciplined body, which pursues control and predictability.

Contesters, on the other hand, contrasted with conformers and often referred to notions of 'beating asthma' or 'fighting it' (Owton and Allen Collinson, 2014, p. 14). Some demonstrated a 'fighting' attitude and wanted to challenge themselves physically in a bid to overcome asthma and prove their self-worth (Owton & Allen Collinson, 2014). Although contesters often wanted to fight against their symptoms, this often jeopardised their health. For contesters, having asthma was not only considered as an attack on the body, but an attack on their sporting self, provoking anger and frustration (Owton

& Allen Collinson, 2014). Contesters also fought against their prescribed treatment regimens, similar to Adams et al.'s (1997) 'deniers' and 'distancers'. The resistance to use medication was often linked to the contesters own somatic knowledge of their body; they listened to their own bodies in deciding whether they required medical help (Owton & Allen Collinson, 2014). This 'auditory work' and monitoring of symptoms was multi-sensory according to Owton and Allen Collinson (2014), as the contesters also listened to their proprioceptive feelings, including their lungs. This somatic awareness of the asthmatic body was even more evident in the third ideal type; the creators (Owton & Allen Collinson, 2014).

Creators experienced less anxiety and panic and viewed asthma as something to be dealt with and managed, rather than perceiving it as something that was threatening to their identity. In turn, creators were more likely to take responsibility for managing their condition (Owton & Allen Collinson, 2014). Having asthma meant learning about their breathing patterns and flow in sport, in order to manage asthma accordingly. Owton and Allen Collinson (2014) explained that this became a valuable source of information for creators. They became 'finely somatically attuned', sharing some resemblances with contesters on this aspect (Owton & Allen Collinson, 2014, p. 19).

Exploring data in this way can help others to resonate with those with asthma and to provide what Allen-Collinson et al. (2016, p. 3) termed as 'somatic empathy', which is a feeling of being able to understand another's lived experience, or to imaginatively inhabit another's body (Merleau-Ponty, 2001). Despite an interest in asthma and sporting embodiment, investigations of the corporeal implications of asthma and the combination of asthma and exercise and sport remain limited. To investigate the body is to acknowledge that the physiological is always connected to and is an expression of the body's intentionality (Merleau-Ponty, 1962). According to Leder (1990), in support of Merleau-Ponty (1962), the body is always directed at something. The following section (see section 3.5.1) discusses Leder's (1990) theorisation of the body in further detail.

3.5.1 The Absent body (Leder, 1990)

In his seminal work, Leder's (1990) phenomenological approach considered the role of the body in lived experience. Commensurate with Merleau-Ponty (1962), Leder (1990) explained that the lived body provides a person's way of being in the world. Leder's (1990) main premise was that the body is often a thematic object of a person's experience when they are engaged in purposive action, such as breathing or engaging in interaction with others. Thus, corporeal absence is central to Leder's (1990) proposition; the body is absent from conscious awareness and disappears from one's attention, as

they *"…dwell in a world of ideas"* (p.1), rarely paying conscious attention to their *"…physical sensation or posture"* (p. 1). Merleau-Ponty (2002, as cited in Zeiler, 2010) described the tacit "*self-givenness*" (p. 4) of the body and how individuals can be bodily self-aware without reflecting on how they position their bodies or move them; this is when they are pre-reflectively aware of their bodies. Pre-reflective awareness enables individuals to act without thinking about movement or motion (Zeiler, 2010); Leder (1990) called this 'bodily dis-appearance'. Dis-appearance occurs when the mind and body remain in harmony during movement, for example, an able-bodied jogger will not normally consider how he moves his/her legs during exercise (Zeiler, 2010). Merleau- Ponty (2014) added that individuals learn how to incorporate specific skills into what he calls their 'body schema', which refers to their body's systems of sensory-motor abilities[7]. These learned skills become part of their pre-reflective bodily knowledge, which subsequently enables them to keep their body in the 'corporeal background' during movement (Leder, 1990). Leder (1990) drew on Merleau-Ponty's (2014) conceptualisation of pre-reflective bodily self-awareness and theorised the concept of the 'absent body', which is premised on the body's ability to remain in the 'corporeal background'. This happens until particular physiological experiences such as symptoms of asthma, cause the body to enter into direct consciousness; this is what Leder (1990) termed as 'bodily dys-appearance'.

In cases of bodily dys-appearance, an individual attends to his/her body as a thematic object of experience and moves into a state of reflective bodily self-awareness (Merleau-Ponty, 2002). Attention is directed towards the individual's body to help them understand more about their "*bodily feel*" (Zeiler, 2010, p. 4) and reminds them of their restricted capabilities (Leder, 1990). Leder (1990) used the Greek prefix 'dys' (which signifies 'bad', 'hard', or 'ill') to develop the term 'dys- appearance' (p. 84). The dys-appearance of the body happens when the body appears to the individual as "*ill*" or "*bad*" (Leder, 1990, p. 84), for example, when symptoms such as breathlessness, chest tightness or wheezing occur during exercise and/or sport. An example of how a person with asthma might shift from a pre-reflective state of bodily awareness to a reflective state is described below in reference to the symptoms of asthma during exercise or sport.

Prior to the experience of breathlessness during exercise, for example, the individual will have been pre-reflectively aware of his/her body. When one begins to experience the discomfort of breathlessness, they move to a reflective state of bodily awareness when they are drawn to the hurt

[7] Our sensory-motor abilities normally function without perceptual monitoring. Merleau-Ponty (2002, p. 166) stated that it is *"knowledge in the hands, which is forthcoming only when bodily efforts are made".*

body part. Here, the body appears to him/her as "*bad*" or "*ill*" (Leder, 1990, p. 84). Thus, prior to the experience of breathlessness, the individual remained the "…*centre from which the rays of intentionality radiate[d] outward to the world"* (Leder 1990, p. 74). When he/she attends to their injury or pain, this intentionality is disrupted (Zeiler, 2010). In this way, the pain of breathlessness disrupts the sporting person's mind-body-world relation (Zeiler, 2010). Leder (1990, p. 73) argued that pain can cause a "*spatiotemporal constriction*" for the person. Zeiler (2010) argued that prior to the experience of the pain, the individual's attention might have been focused on other aspects of their life but is then drawn in to their bodily 'here and now' when they experience pain (Zeiler, 2010). Shilling (2012) drew on Zeiler's (2010) arguments and suggested that when an individual experiences pain which has the potential to "*take [their] breath away*" (p. 218), for example, when he/she feels breathless, this removes the individual from focusing on other purposeful activities, such as sport and/or exercise.

According to Scarry (1985), a person can become lost in a world of bodily pain, one which is characterised by agony and anguish. This is reminiscent of the effects of an asthma attack, where some of the participants in the current research described feelings of penetrating pain, being unable to breathe and waiting for the attack to come to an end. During the asthma attack, it might be that the person is unable to think of anything other than the 'body-in-pain' (Zeiler, 2010) and it can often seem impossible to express how he/she is feeling during the pain (Levinas, 1974). According to Scarry (1985, p. 4), the pain "…*resists*" and "…*destroys*" language. Levinas (1974, p. 238) explained that intense pain can "…*subjugate the self fully"*, where the individual remains "…*held fast*" in pain (Levinas, 1974, p. 52). Bullington (2009, p. 106) expanded on this and argued that the self "…*becomes*" pain and the 'body in-pain' (Zeiler, 2010) appears to him/her as something that is "…*swelling to fill the entire universe*" (Scarry 1985, p. 35).

In his work, Leder (1990, pp. 11-102) described three types of phenomenologically-inspired concepts: the ecstatic body; the recessive body; and the dys- appearing body; all three of which are summarised in the table below (see Table 6, p. 91).

The ecstatic body.	The body projects itself outwardly to the world.
The recessive body.	The body retreats from its own conscious perception and control. The body utilises its sensory controls, which are divided into three categories: Interoception: denotes to all sensations of the internal organs of the body, or the viscera Exteroception: refers to the five senses, which are exposed to the external world Proprioception: which is the body's "*sense of balance, position, and muscular tension, provided by receptors in muscles, joints, tendons, and the inner ear"* (p. 39).
The dys-appearing body.	The body disappears, as long as perception does not present with problems. In this case, to 'disappear' is to simply not appear. The term *disease* (dis-ease) illustrates the loss of comfort and possibility of physiological disruption one might experience. Differentiates between 'disappearance' and 'dys-appearance'; 'dys' being a pre-fix suggesting 'bad, uncomfortable, abnormal'. The body is no longer absent from experience. In the case of health: the body is alien by virtue of its dys-appearance.

Table 6. Leder's (1990) body types, adapted from Leder (1990).

Additionally, Leder (1990) argued that there are social implications to the 'dys-appearance' of the body. According to Leder (1990), when the body dys-appears, a person's self-consciousness can increase when the body acts different to what is expected whilst in the presence of others. This shares similarity with Goffman's (1956) theorisation of self-presentation (see section 3.3 for further detail). Goffman (1956), like Leder (1990), explained that when social interaction is disrupted by inappropriate conduct, people can become acutely conscious of their bodies. When this happens, the individual might feel embarrassed (see section 3.4) and this can cause dryness of the mouth or stiffness of the muscles, which can further disrupt the interaction (Goffman, 1956). So, although one does not experience physical pain, the body can 'dys-appear' due to heightened levels of bodily awareness during social interactions.

There have been fewer studies that have explored when the body appears to the person as "*good, easy, or well*" (Zeiler, 2010, p. 2), which is contrary to bodily dys-appearance (Leder, 1990). For example, in the current research, the body might appear as "*good*" when the sporting body performs without experiencing symptoms of asthma. Zeiler (2010) coined the term 'eu-appearance' of the body to describe a state of positive bodily awareness. The following section (see section 3.5.2) discusses Zeiler's (2010) theorisation in further detail.

3.5.2 Eu-appearance of the body (Zeiler, 2010)

In order to develop a nuanced understanding about bodily self-awareness, Zeiler (2010), like Leder (1990), drew on Merleau-Ponty's (1960) ideas about the body to understand how the body appears to a person in various ways. Zeiler (2010, p. 1) explored how the body appears to the individual as something positive, which she termed a '*eu-static*' bodily mode of being, combining the Greek '*eu'*, which means well, good, or easy and '*statis'*, which means to stand. Zeiler's (2010) argument is that "…*the transformation into the bodily as physical [does not] always mean discomfort and malaise"* (Plugge 1970, as cited in Young, 2005, p. 50-51). Hence, the body can appear to the person as positive, rather than one characterised by discomfort (Zeiler, 2010).

Zeiler (2010) explained that the body can remain in a eu-static state of bodily awareness during exercise, and this concept is therefore relevant to the current research. Zeiler (2010) provided an example and suggested that when someone engages in swimming, he/she might enjoy the warmth of the water and the strength of their body in the water. As long as one remains aware that the body is 'good', 'well', or 'easy', the body can be considered 'eu-static' (Zeiler, 2010). In the current research, this can be extended to people with asthma who engage in sport and/or exercise, who search for ways to remain in a 'eu-static' mode of being (Zeiler, 2010) (see chapter Five for further

discussion). According to Zeiler (2010), as long as the individual does not attend to his/her body as a thematic object of experience, being in a 'eu-static' bodily mode is normally pre-reflective (Zeiler, 2010,

p. 15). Unlike bodily dys-appearance (Leder, 1990), the mind-body-world remain in harmony and intentionality remains undisrupted, nor is there the threat of bodily discomfort (Zeiler, 2010).

Furthermore, the eu-appearance of the body can have social implications. As previously mentioned in Leder's (1990) analyses of the absent body and bodily dys-appearance (see section 3.5.1), a person can become acutely aware of their body when others look at them. In cases of bodily dys- appearance (Leder, 1990), people might become self-conscious due to his/her body acting different to what is normally expected, whereas in bodily eu-appearance, people might look for positive responses from others to improve their position in the social interaction. A eu-static state might aid the social interaction, whereas bodily dys-appearance can heighten feelings of embarrassment and subsequently heighten bodily self-consciousness (Zeiler, 2010). Thus, Zeiler's (2010) concept of the 'eu-appearance' of the body was applied to understand how the asthmatic, sporting body appeared as 'good' and 'well' in both a sporting context and an everyday context for South Asians.

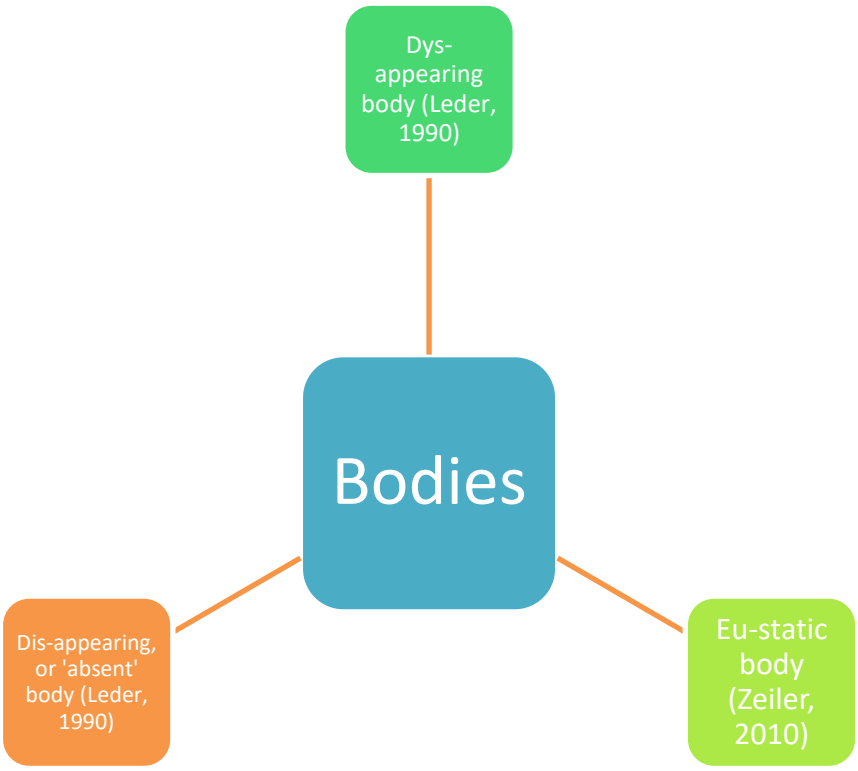

Figure 6. Different types of bodies, according to Leder (1990) and Zeiler (2010).

The current research used Goffman's (1959) self-presentational insights to understand how UK- resident South Asian adults manage their self-presentation, with regard to the presentation of their asthma-sporting self, in order to present an idealised version of themselves. Additionally, Goffman's

(1969) discussion of stigma was applied to understand how UK-resident South Asian adults with asthma experience stigma, and how they manage their stigmatised identities. Furthermore, commensurate with a phenomenologically-inspired approach, the current research applied Leder's (1990) concept of the absent body and Zeiler's (2010) notion of the 'eu-static' body to understand how UK-resident South Asian adults with asthma manage their asthma sporting body-self in everyday life, how cases of bodily dys-appearance are assessed, and how the asthma-body can appear as both 'bad' and 'good' during sport and/or exercise.

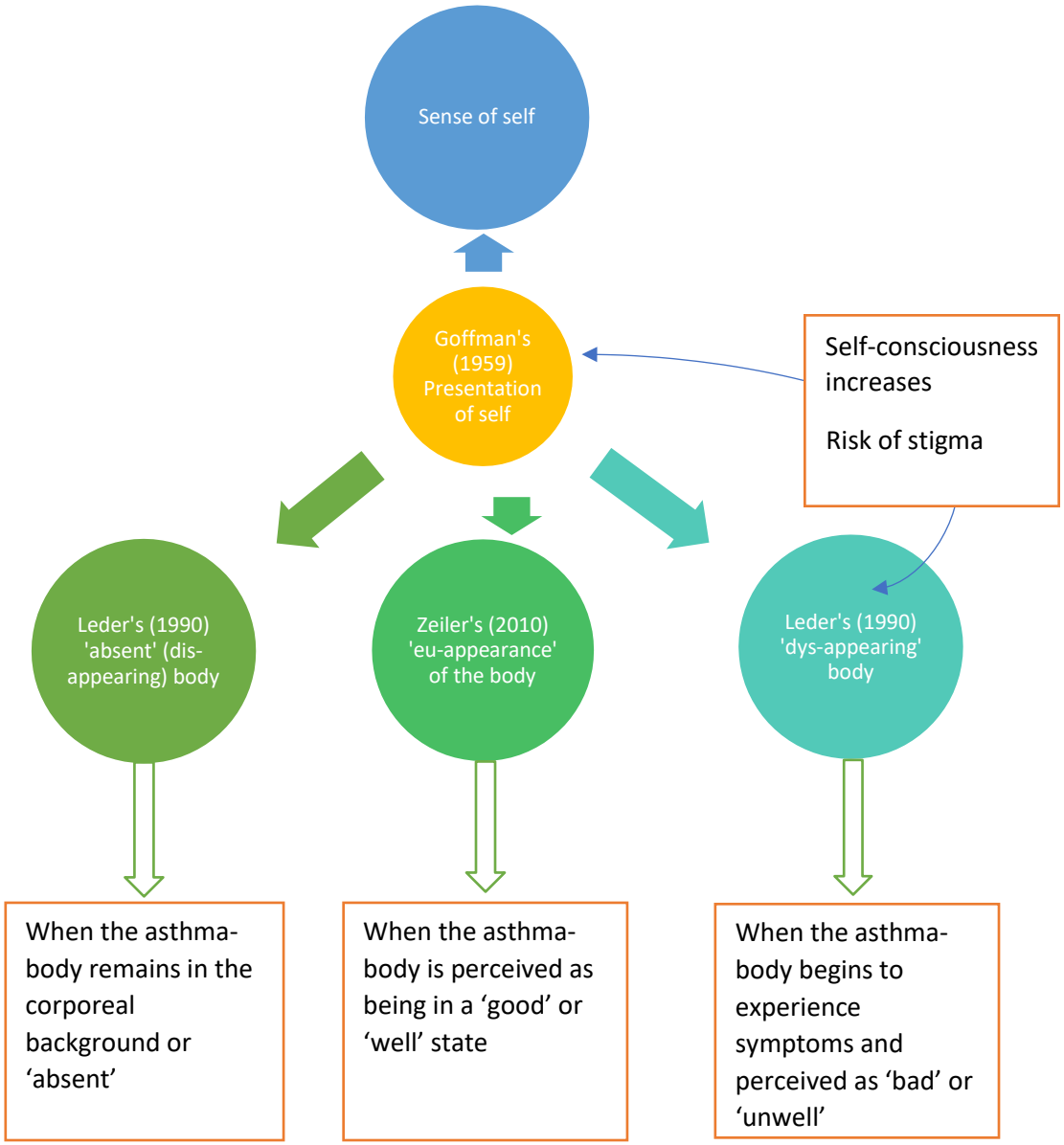

Figure 7. Conceptual model of theoretical insights, as applied in the current research.

3.6 Summary of conceptual frameworks

This chapter has provided further detail on the theoretical perspectives through a symbolic interactionist and phenomenologically-inspired approach. Erving Goffman (1959; 1963) provides a coherent and overarching framework, in which to understand how UK-resident South Asian adults with asthma manage the presentation of their asthma self and exercising and/or sporting self in different contexts. I have also outlined the work of Drew Leder (1990) and Kristin Zeiler (2010). These theorists provide a combined lens in order to analyse and understand the lived experiences of asthma and sporting embodiment. This leads to the next chapter where the design, methodological techniques and data analysis is outlined. It also provides a rationale for the way the data has been represented and how my role as the researcher influenced the research process.

Chapter Four: Research methodology

4.1 Introduction

The previous chapter provided a review of the literature, where it identified a paucity of literature representing the UK adult South Asian population and outlined the need to provide further insight into the lived experiences and embodiment of South Asians with asthma, who participate in, or have taken part in exercise and/or sport. Lived experiences or individual subjectivity is understood as the lifeworld that an individual occupies, one which is highly personal, and it is this individuality that is significant to a person's position in the lifeworld (Lawthom & Tindall, 2011). The phenomenological concept of the 'lifeworld' is defined as the world of lived experience inhabited by individuals as conscious beings and includes the way in which phenomena appear to individuals in everyday life (Husserl, 1970). Lifeworlds include mutual features such as embodiment (Ashworth, 2003).
Embodiment, the focus of this research, is understood as our:

> *"…felt sense, or our subjective meanings of the lived experience of the body that we communicate with and come to know and understand our world; it is through our bodies*" (Lawthom & Tindall, 2011, p. 14).

As lived experience of asthma may be considered highly meaningful to participants, an investigation using research methods, which can help elicit their thoughts on their social world and reality was required (Bowling, 2014). Commensurate with a symbolic interactionist perspective, social worlds are understood as 'the world around individuals', which is constructed via social interaction (Ladson-Billings, 2000; Schutt, 2019), along with the construction of the identities of its social actors (Johnson & Levine, 2008).

Benner (1994) argued that individuals may experience several phenomena which might stimulate their search for meaning. This can include the experience of illness and individuals may want to make sense of their identities, their sense of self and their lifeworld when they are confronted with a health threat, in this case, asthma. This was seen in the current study when there were times when participants minimised their asthma status or looked to use culturally based treatments (see sections 5.2-5.4).
Thus, this research project uses a qualitative, interpretive, phenomenologically- inspired methodological approach and uses interpretative phenomenological analysis (IPA) to record and analyse a first-person experiential perspective on: asthma; sport and/or exercise and South Asian

culture. The context for developing the research methodology was related to the understanding that social worlds and lifeworlds of asthma, sport and/or exercise and South Asian culture were considered meaningful to the participants. At the same time, the experience ofasthma was understood as an illness which was lived through the body, with a particular focus on the *'lived body'*, that is, the notion that individuals and their consciousness are perpetually embodied within the body (Nettleton & Watson, 1998). For example, people with asthma can be physically challenged during exercise and/or sport due to their symptoms; they often feel breathless or wheezy during exercise and/or sport participation and may experience an exacerbation of asthma (Del Giacco, 2015). This chapter describes the different methods used to record, analyse, and interpret the rich, embodied experiences and the participant's engagement with asthma from their own perspective.

First, this chapter briefly describes the interpretivist paradigm and provides the rationale for adopting an interpretivist approach in this research. Second, sampling practices related to the current research and a brief overview about the participants is offered. Third, the chapter moves onto introducing and outlining the qualitative methods selected for this project. Fourth, as part of a reflexive approach, my role as the researcher is considered. Fifth, the essential principles of ethical practice such as confidentiality, anonymity and representation of data is presented. Sixth, a detailed consideration about the decision to use IPA is provided, together with the steps towards successful implementation of IPA. Seventh, a discussion about the validity of the present research is offered. Lastly, a short discussion about the use of a creative approach to the data is offered.

To begin, it was important to consider the philosophical foundations or research paradigms that support social science research in its development, and the ways in which data are understood and interpreted (May, 2011; Scotland, 2012).

4.2 Philosophical paradigms

In order to identify the most appropriate approach for this research project's aim and objectives, an exploration of research philosophies and methodologies was undertaken. Research is constructed by specific beliefs and theories about how the social world is perceived, what there is to know about it and how best to understand it (Scotland, 2012). Philosophical paradigms are known as belief systems and hold particular characteristics, methods and practices, which are used to direct a researcher's knowledge (McKerchar, 2008; Antwi & Hamza, 2015). Johnson and Christensen (2008) described a paradigm as *"…a perspective about research held by a community of researchers that is based in a set of shared assumptions, concepts, values, and practices"* (p. 31).

Philosophical paradigms are understood in relation to their axiological, ontological, epistemological and methodological assumptions (Guba, 1990; Sparkes, 1992). Axiological assumptions are associated with the nature of ethics or the value-stance taken by the researcher (Mertens, 2007; Creswell & Poth, 2017). Ontological assumptions are related to *"…the nature of reality and defined as the study of being"* (Crotty, 1998, p. 10). Assumptions according to one's epistemology are associated with how one perceives the truth or the social world dependent on the beliefs and the ways in which knowledge is acquired and communicated to others (Guba & Lincoln, 1994).
Methodological assumptions are based on the strategy, or plan of action and use of methods, and is the relationship between the selection and utilisation of methods to provide the desired result (Crotty, 1998). In the current research, interviews were the main method of data collection because it enhanced the understanding of individual experiences of asthma, sport and/or exercise in the UK-resident adult South Asian population. In short, these four assumptions shape and influence how researchers collect, analyse and interpret data. Next, the methodological approaches used in research are considered and the methodological approach adopted in the current study is described in further detail.

There are two distinct methodological approaches for collecting information in research (Grinnell & Unrau, 2005). The first, known as quantitative research is often based on the philosophy of cause and effect, for example, quantitative researchers might examine the relationship between two or more variables (Thanh & Thanh, 2015). This approach has a close connection to the theoretical principles of positivism (Crossan, 2003), and it often uses methods such as questionnaires and surveys (Denzin & Lincoln, 2018). In contrast, the second methodological approach known as qualitative research can be used to draw wider inferences about the nature of the social world, studying the meanings which people attach to a phenomenon, for example, actions, beliefs and social world values from the perspective of those being studied (Denzin & Lincoln, 2018). Qualitative research usually involves varied approaches (e.g., ethnography), and methods such as interviews, focus groups and observational techniques (Denzin & Lincoln, 2018). Although a quantitative approach may also be concerned with meaning by searching for differences in thoughts and behaviour, qualitative research can seek out and illuminate meanings related to these differences (Denzin & Lincoln, 2018). In the current research, a qualitative approach in the present study enabled me to learn about the lifeworld and social world of UK-resident South Asian adults with asthma and their exercise and sporting experiences. For example, instead of asking participants to tick a box about which types of sport and/or exercise they participate in, a qualitative approach uncovered the reasons why they take part

in these specific types of sport and/or exercise, demonstrating insight and detail about such sporting activities and how asthma, sport and/or exercise and South Asian culture play a role in their lifeworld.

According to Creswell (2013), the qualitative methodological approach has been informed by several philosophical paradigms, including interpretivism. Although there are several established paradigms in the social sciences, I focused on the interpretivist paradigm in the current study. The interpretivist paradigm was included because qualitative research has often been situated within this paradigm (see section 4.2.1) (Willis, 2007; Nind & Todd, 2011; Silverman, 2015). Interpretivists believe that people are different from objects and the study of human behaviour subsequently necessitates a methodology that focuses on these differences (Prus, 2006). Interpretivists consider human behaviour as an interpretive, interactive process, actively created by individuals in interaction with each other (Prus, 2006). Thus, human life is investigated as it is experienced and is concerned with the meanings people attach to their situations (Prus, 2006). Positivists are critical of the interpretivist approach, asserting that the interpretivist approach is subjective and unscientific because of: i) its emphasis on the meanings people attach to their behaviours and ii) because these meanings cannot be operationalised, that is, counted and statistically measured (Prus, 2006). For example, UK-resident South Asian adults with asthma might offer differing experiences of asthma, thus rendering them unquantifiable. Positivists argue that their measurements of human behaviour are much more scientific because they develop objective measurements of cause and effect (Prus, 2006). In response, the interpretivist approach argue that the study of human behaviour is the study of lived experiences and that the investigation of human experience is embedded in people's meanings, interpretations and interactions (Prus, 2006; Van Manen, 2016). The interpretivists argue that by neglecting the interpretive and interactive processes of human behaviour, the positivist approach discount the social essences of human behaviour (Prus, 2006; Van Manen, 2016).

Additionally, Lincoln and Guba (1985) argued that individual perceptions of reality cannot be clearly explained, using a wholly objective approach. The main reason for this is that different experiences might hold different meanings for different people (Giddens, 2001; 2010). Human behaviour and experience are believed to vary between each individual and are specific to one's social context (Giddens, 2001; 2010). It was understood that a South Asian adult's lived experiences might include differences in thoughts, attitudes, actions or behaviours and so forth. The positivist approach was therefore seen as an unreliable paradigm for the fulfilment of the aim and objectives of the current research, since it may not have been able to account for the variances in beliefs, emotional states and conduct in the experience of asthma and sports and/or exercise. Rather than seeing these differences

as problematic, interpretivism embraces them and their idiosyncrasies. Philosophers such as Sarte (1956), Merleau-Ponty (1962), Husserl (1982) and Heidegger (2005) believed that human experience is subjective and is embodied in the behaviour, feelings, and perceptions of people, which positivist approaches might not account for. In this way, the qualitative researcher can establish patterns in the meanings related to specific events and occurrences (e.g., the experience of sport and/or exercise for people with asthma), discover agreements or conflicts over the understandings of particular aspects (e.g., the origin of asthma), and reflect on what this might mean for individuals. According to Rubin and Rubin (2012), interpretive social research involves learning about what events or occurrences mean for people and understanding their perspective about what has happened to them. In the current research, the interpretivist approach enabled me to study the ways in which UK-resident South Asian adults experience asthma, how they physically and mentally adapt to exercise and/or sport and how they make sense of their condition and their sporting and/or exercising experiences.

The value of the qualitative approach lies in the ways these patterns of, and differences in experiences can be explored. There has been some research using qualitative methods such as interviews, to understand the meaning of medicine for South Asian adults with asthma and their medication-taking behaviour (e.g. Griffiths et al., 2001; Hussein & Partridge, 2002). Limited qualitative research, as well as some outdated evidence, has suggested that decisions are made in the context of the South Asian person's beliefs, attitudes and preferences (Hazir et al., 2002; Griffiths et al., 2001; Lawton et al., 2006; Shivbalan et al., 2005; Lakhanpaul et al., 2017). Furthermore, there has been increased attention on qualitative asthma researches that try and understand how compliance with medical regimes can be increased in South Asian children and adolescents, in order to enhance the self-management of children and adolescents with asthma in the UK (Lakhanpaul et al., 2014; 2015; 2017; 2019). Academic research investigating exercise and sport within the UK-resident South Asian cohort has opted to investigate the barriers and facilitators to such participation in order to improve participation rates (Jepson et al., 2012; Koshoedo et al., 2015; King & Little, 2017). However, in this way, questions about why South Asian adults may dislike taking medication, or why they choose to use different types of non-pharmacological treatment are not always addressed. Perhaps questions such as how a South Asian person's culture might influence their medication-taking behaviour, or how they feel about taking such medications need to be asked. Therefore, to understand and explore these factors, an approach suitable to provide richly detailed descriptions of the experiences through the use of participants' subjective words, rather than by use of objective measures was necessary. The paradigm explored in response to this was the interpretivist paradigm.

4.2.1 Interpretivism

Interpretivism often challenges the positivistic approach to research, as it highlights the role of interpretation and assimilates human interest into the research process. According to Myers (2009), interpretivists:

> *"…assume that access to reality (given or socially constructed) is only through social constructions such as language, consciousness, shared meanings, and instrument.*" (p. 38).

Interpretivism is generally associated with the idealist philosophy and includes approaches such as symbolic interactionism (Scotland, 2012). Interpretivist approaches are known to be subjective in nature and agree that meaning is created independent of consciousness (Collins, 2019). Furthermore, interpretivist research accentuates the value of meaning and may employ several different methods to reflect diverse perspectives (Creswell, 2013). Interpretivism also adopts a relativist ontology, which believes reality is intersubjective and is based on experiential meanings and understandings (Scotland, 2012). Several methodologies including interviews and observation are regularly used by interpretivist researchers (Scotland, 2012). Positivism, on the other hand, might rely on experimental data or the more common statistical data (Halfpenny, 2014). In relation to the current research and the investigation of UK-resident South Asian adults with asthma, interviews were utilised to gain knowledge about the experience of asthma, sport and/or exercise and the South Asian culture and relied on the interpretation of and understanding of the meanings that participants attached to their behaviour.

Interpretivism relies on human interpretation of the social world and applies both the researcher's and participant's understanding of the world to the phenomenon being explored (Cresswell, 2009). While the positivist approach believes that the social world involves *"…hard, tangible facts that can be measured*" (Sparkes, 1992, p. 20), the goal of the interpretivist ontology and epistemology is to view the social world as something *"…that is constructed within individuals' subjectivities', interests, emotions, and values"* (Sparkes, 1992, p. 25). Interpretivist researchers argue that the social world is associated with what the individual believes (Sparkes, 1992; Markula & Silk, 2011), although it does not suggest that the mind *"…creates what people say and do"* (Smith, 1989, p. 74), or that the social world is solely present in an individual's mind (Nelson, Groom & Potrac, 2014). Instead, it argues that the mind influences how people interpret behaviour and encompasses the meanings that individuals assign to their intentions and motivations (Smith, 1989, p. 27). It is with this where interpretivism lays its claim, in the domain of meaning making (Nelson et al., 2014); a position which makes the use of

positivistic methods' unsuitable for explanation (Lazar, 2004; Seale, 2018). Some examples of interpretive research approaches include ethnography, auto-ethnography, and case studies (Owton, 2017).

In this project, I identified as an in-depth qualitative researcher. A comprehensive and in-depth qualitative researcher's intention is to remain close to the research process, rather than acting as a disembodied objective scientist (Gould & Nelson, 2005; Owton, Bond & Todd, 2014). In line with the interpretivist approach, in-depth qualitative researchers recognise, reflect on and integrate their emotional experiences into the research process (Tillman-Healy & Keisinger, 2001). Thus, the qualitative researcher's voice remains explicitly present in their research (Fink, 2000; Owton, 2017). The researcher-participant relationship is acknowledged, which produces data emerging from the exchanges, which demonstrates that qualitative research cannot be replicated in the same way (Owton, 2017). In the current research, positivism would usually require me to 'detach' myself from emotional connection with my participants because positivist principles would typically require me to remain objective in the research process. However, this would make it difficult to interpret and understand what my participants might have been trying to tell me. For example, in the current research, there was a need to build rapport around asthma and the impact of the condition to help me understand more about how it affected my participants.

As an in-depth qualitative researcher, I searched for understandings from an interpretivist perspective, inspired by a symbolic interactionist and phenomenologically-inspired approach. A phenomenologically-inspired approach enabled me to explore the awareness of the body and its bodily sensations and its relationship to the world. Moore (1998, p. 3) articulated that the body is *"…more than a tangible, physical, corporeal object"*, it is an *"…enormous vessel of meaning"* of paramount significance to the person and society; *"…the body is a social object"* (Waskul & van der Riet, 2002, p. 510). Waskul and Van der Riet (2002, p. 488) explicated that the body *"…does not inhabit"* a stagnant, object body but is *"…subjectively embodied in a fluid, emergent and negotiated process of being"*; the body is in a relationship with itself and with others (Allen-Collinson, 2009). Similarly, the symbolic interactionist approach believes that individuals' consciousness is not separate from their interactions with the world and argues that the ways in which individuals handle their bodies in social situations is crucial for their self and identity (e.g. Goffman, 1959; 1963; 1971). Symbolic interactionists consider four premises to support their study of human behaviour, which have been previously mentioned (see section 3.2). Therefore, this research explored how UK-resident South

Asian adults acted towards things associated with asthma, sport and/or exercise and how these meanings were derived. Additionally, and significant to both the philosophies (phenomenology and symbolic interactionism) is the premise that individuals live in a world of meanings (Woodgate, 1998). Both theoretical perspectives focus on the significance of meaning making in everyday interaction with the world and were used to guide this research to offer an insight into UK-resident South Asian adults meaningful asthma embodiment, the ways in which South Asian sporting adults articulate their embodied sporting and/or exercising experiences and how these individuals are guided by the meanings they assigned to their condition.

To assist this qualitative, interpretivist enquiry, an appropriate research analysis technique was required. In line with the interpretivist principles of embracing subjectivity and individual interpretation, interpretative phenomenological analysis (IPA) was selected for this research (Smith, Harré, & Van Langenhove, 1995). IPA focuses explicitly on sense making by using first-person accounts to explore how the world is humanly experienced (Spinelli, 2005); "*Human beings are sense-making creatures, and therefore the accounts which participants provide will reflect their attempts to make sense of their experience"* (Smith, Jarman & Osborn, 1999, p. 4). Therefore, IPA aligns with a phenomenologically-inspired and symbolic interactionist perspective, preferring to explore individual perceptions of phenomena from a phenomenologically-inspired perspective, and drawing out the *"…human meanings"* (King et al., 2008, p. 81) in the lifeworld via a process of interpretation from a symbolic interactionist perspective (Smith, 1996; Smith et al., 1999). Therefore, IPA was utilised in this research to gain a deeper understanding of how asthma, sport and/or exercise is experienced by UK-resident South Asian adults using first person accounts with the goal of elucidating the phenomena of asthma, sport and/or exercise in the UK-resident South Asian population. Sampling procedures (see section 4.3), participant demographics (see section 4.4), recruitment strategies (see section 4.4.1) and the method of IPA (see sections 4.9-4.10) are now discussed in further detail.

4.3 Sampling

Participants were selected using a combination of convenience and snowball sampling. The sample consisted of 14 participants (12 females, 2 males). A presumed lack of interest from South Asian males appeared to make this sample gender imbalanced. The number of participants (n=14) was deemed appropriate due to the idiographic nature of this research. Within qualitative, interpretative research such as IPA studies, the sample size is argued not to be indicative of the quality of a study, but rather

the richness of data and commitment to analysis for each and every individual involved (Tzanidaki & Reynolds 2011, p. 376). Eatough and Smith (2017) explained that studies using IPA commonly use small and situated samples to ensure that each individual can be attended to idiographically, or individually case-by-case, before a comparative analysis of the data corpus is attempted.

Previous research has stated that there is a temptation to include large sample sizes in qualitative IPA studies, particularly within research fields where quantitative research methods often dominate (Eatough & Smith, 2008; Pietkiewicz & Smith, 2014; Eatough & Smith, 2017). However, Smith and Osborn (2004) proposed that the sample size should be kept lower in order to retain IPA's idiographic focus and suggested that the depth and richness of the data with a small sample size can be achieved by interviewing participants more than once (Snelgrove, Edwards & Liossi, 2013; Rodriguez & Smith, 2014). A strategy such as this demonstrates IPA's commitment to treating each individual case-by-case, whilst drawing out any patterns in a rich and detailed context (Eatough & Smith, 2017; Smith, 2019). Eatough and Smith (2017) noted that although IPA does not want to overlook the particularities of each individual's lifeworld, attempting to emphasise the convergence

and divergence between individuals' lifeworlds can be more insightful when they appear from a case-by-case method. Through detailed examination of each case, the number of participants (n=14) provided the depth and richness within the data and embedded patterns of convergence and divergence between participants' lives, thus aligning with IPA's commitment to idiographic emphasis. In the current research, each case was treated individually, and individual theme tables were produced (see Appendix 8), commensurate with IPA's idiographic focus.

4.3.1 Purposive sampling

The practice of sampling involves identifying people from specific populations, in order to conduct the research effectively (Denscombe, 2014). Sampling procedures in IPA are normally influenced by the research strategies selected to guide the research (Denscombe, 2014). Qualitative, interpretative research such as that utilising IPA, considers purposive sampling as the dominant sampling approach (Pietkiewicz & Smith, 2014; Eatough & Smith, 2017). The purposive sampling approach is used to identify participants who can provide information that can be explored in depth and which is situated within particular categories, including specific types of illness and/or ethnicity (Mertens, 2014). IPA uses purposive sampling to elucidate a specific set of research questions, in order to develop a comprehensive interpretation of the data (Barbour, 2014; Eatough & Smith, 2017). Purposive sampling requires the researcher to evaluate the appropriate criteria and the restrictions for the study (Flick,

2014). The sampling criteria for the current research required participants to: self-identify as South Asian[8], be over the age of 18, have received a medical diagnosis of asthma[9], to currently be taking prescribed medication for asthma at the time of recruitment, and to engage in/or have previously engaged in exercise or sport. I did not actively sample for gender in the current research, hence the majority of participants were female by coincidence. Several male candidates were interested in taking part, however after repeated attempts to contact them, they chose not to participate. In conjunction with purposive sampling, a snowball sampling approach was used to recruit further participants for this research.

Snowballing refers to the connections developed enabling more participants to take part, increasing over time (see section 4.3.2) (Thompson, 2002).

4.3.2 Snowball sampling

The snowballing method was used to include participants who were known to the initial participant sample. For example, participants recruited via the purposive sampling approach informed me of other participants who would fit the sampling criteria. In the current research, five participants were recruited via the purposive-snowballing approach. One of the main advantages of snowballing is that the accumulation of numbers is sometimes quicker than the purposive sampling approach (Babbie, 2016). This was the case in the current research, where more often the female participants involved, recommended other females take part. Babbie (2016) stated that new people can be approached to take part in research because they have been supported by the person who has named them. This provides an added advantage in terms of trust, since the nominator can be named as a reference, which Smith, Jarman and Osborn (2009) suggested enhances the credibility of both the researcher and the study itself.

In addition, the snowball sampling approach enables a wider focus (Babbie, 2016). The current research was not restricted to a prescribed location, although all participants were residents of Leicester in the UK at the time of the first interview. The current research was also restricted to people over the age of 18 due to limited academic evidence in the UK-resident South Asian adult population with asthma (see section 2.2), and therefore the current research aimed to augment the paucity of literature in this area.

[8] The term 'South Asian' has been defined at length in chapter One (see section 1.9).

[9] Participants reported that they had received a medical diagnosis.

A total of 14 participants took part (see Table 7, pp. 109-117). Follow up interviews were completed with nine participants; 5 were face-to-face interviews; 2 were telephone via Skype interviews; 2 were email follow-ups (see section 4.5). As previously discussed, IPA is committed to the idiographic method (see section 4.3), which has consequences for the sample size. In order to retain the idiographic focus, Eatough and Smith (2017) suggested keeping the sample size smaller for IPA-focused studies, with the norm ranging from one to thirty participants (Brocki & Wearden, 2006). To achieve the idiographic commitment in IPA research, I chose to recruit a maximum of 30 participants. According to Crouch and McKenzie (2006), having a smaller sample size in qualitative research can benefit the researcher, as it can help to build and maintain a close relationship with the participant, improving the open and frank exchange of information. In order to achieve this in the current research, the sample size remained small, helping me to forge close relationships with each participant.

Some of the participants had been diagnosed with late onset asthma (n= 2), whilst the majority were diagnosed when they were younger (n= 12). Participants took part in a varying amount and type of exercise. Asthma had occasionally been perceived by participants to dictate the types of exercise and sport they could participate in, often influencing how much they could do and their decision to take part in exercise and/or sport, or in some cases, ceasing participation. Severity of asthma differed (see Table 7, pp. 109-117). Essentially, this research aimed to provide a comprehensive, in-depth depiction of the lived experiences of UK-resident South Asian adults with asthma, sport andexercise, presenting individual accounts from 14 UK-resident South Asian adults. Below, a brief overview of demographic information and a description of the participants' backgrounds is provided (see Table 7, pp. 109-117).

4.4 Participants

4.4.1 Recruitment

Participants were sought out and selected because they had personal experience about the phenomena under investigation. The participants' provided a unique voice and *"…represent(ed) a perspective, rather than a population"* (Smith et al., 2009, p. 49). As previously mentioned (see section 2.4), Rooney et al. (2011) conducted eight focus group discussions with UK-resident South Asian adults with asthma and parents and/or carers of people with asthma from differing ethnic backgrounds. This included individuals from Indian, Pakistani and Bangladeshi communities in London and Edinburgh. According to Rooney et al. (2011), some respondents reported that UK-resident South Asians may be reluctant to get involved in research and thus, recruitment in this population may be difficult, time-consuming and laden with potential barriers. Taking this into account, the

current research employed multiple recruitment approaches to access the UK-resident South Asian cohort with asthma.

Local community recruitment was applied in Leicester and locations were chosen according to their position in the most recent census for the highest presence of South Asian groups. For example, the areas Belgrave (65% of the local population), Rushey Mead (54.7%), Evington (42.2%), Charnwood (42.1%) and Spinney Hills (60.2%) were all considered due to the large ratio of South Asian residents (Ghosh, online, 2014).

The project was advertised using social media platforms including Twitter and Facebook (see Appendix 1). Additionally, an online advertisement (see Appendix 1) was developed, posted and tweeted, garnering some response. Any interested parties were asked to contact me via a De Montfort University (DMU) email address. A copy of the participant information sheet was then emailed to the interested parties for further information. Those who had contacted me via Facebook and Twitter did not contribute to the research. An email advertisement was also sent to all academics and students at DMU, Leicester. A request to post an advertisement on the DMU Psychology's research participation scheme shell was approved. This is a system where DMU psychology students take part in research exchange for credit[10]; 4 participants were recruited via this approach.

All of the participants were aged 18 years or over and self-identified as South Asian or British South Asian (see Table 7, pp. 109-117). All of the participants were asked to determine whether they considered their asthma to be mild, intermittent, moderate, severe or exercise induced (according to Colice's (2004) guidelines and were also asked to specify their prescribed asthma medication. All of the participants identified as either currently engaging in and/or had previously engaged in sport and/or exercise (see Table 7, pp. 109-117). There were no volunteers who self-identified as having Nepalese, Bhutanese, Maldivian, or Afghanistani backgrounds. Therefore, for the purposes of the current research, the term South Asian referred to any person who either had Indian, Pakistani, Bangladeshi, or Sri Lankan ancestral origins, as indicated in section 1.8. Lastly, participants were given the opportunity to have their interview conducted either at DMU or at their home.

[10] DMU Psychology students receive course credits when they participate in research studies, via a 'research participation scheme', or RPS.

Below, some contextual background information about the participants has been provided to help the reader understand more about them. It is a way of 'getting to know' the participants using the information that emerged from individual interviews. All participants have been given a pseudonym and any identifiable details have not been included. These issues have been discussed in more detail in section 4.8.

Participant	Self-described ethnicity	Type of prescribed medication (according to BTS guidelines, 2016)	Type of exercise or sport (and length of participation)	Background
Reena Female Age: 46	Indian Sikh	Budesonide/formoterol fumarate dehydrate (preventer inhaler known as Symbicort turbohaler) (see glossary of terms for more information) Salbutamol (reliever inhaler) (see glossary of terms for more information) BTS step (dose dependent): Step 2	Moderate exercise (cycling, walking dog, weight training)	A widowed mother of three. Her husband experienced severe allergies and had also been diagnosed with asthma. Reena mentioned that she was diagnosed with asthma in adolescence, though she exhibited symptoms in her childhood. She identified as having moderate to severe asthma. Reena explained that she suffered severe bouts of asthma when she was pregnant with her youngest child and consequently had to stop exercising. She now exercises by walking the dog regularly, participating in yoga, cycling, weight training and HIIT workouts (see glossary of terms for a definition).
Nafisa Female Age: 36	British Asian	Beclomethasone in childhood	Moderate exercise	Author and mother of three. Nafisa was diagnosed with severe asthma in childhood and identified as having intermittent asthma.

		Currently only Salbutamol BTS step: 1		Nafisa mentioned that she used to run regularly and had previously taken part in a 5k run and other half marathons. She has been prescribed salbutamol to treat her asthma, although when she was younger, she was prescribed both a preventer inhaler and a reliever inhaler (see glossary of terms for more information).
Aisha Female Age: 53	Indian	Symbicort turbohaler (budesonide/formoterol fumarate dehydrate) (preventer inhaler) Salbulair Easi-Breathe (reliever inhaler) (see glossary of terms for more information) BTS step (dose dependent): 2	Moderate exercise (Swimming, walking)	A part time co-ordinator at a local surgery and mother of two, Aisha was diagnosed with asthma in adulthood (mid 20's) and identified as having moderate asthma. Aisha stated that her daughter has also been diagnosed with asthma and her father (who has now passed) was also an asthmatic. Aisha mentioned that she enjoys swimming, walking and attending the gym and she has been prescribed a preventer inhaler and a reliever inhaler to treat her asthma.
Faheema Female Age: 21	Asian	Preventer inhaler in childhood (no other details mentioned)	None currently – mentioned walking to and from university as physical activity.	A university student (at interview 1) and an employed graduate (at interview 2). She identified as having mild

		Currently Salbutamol (reliever inhaler) BTS step: 1		asthma and explained that she has not been prescribed a preventer inhaler since childhood.
Maryam Female Age: 20	Bangladeshi	Beclomethasone in childhood (see glossary of terms for more information) Currently Salbutamol and red preventer inhaler (no other details mentioned) BTS step: 2 if regular Preventer	Gym equipment at home Attended gym in the previous year (treadmill and other machines)	Maryam was born in Bangladesh and was a university student (at interview 1). She was diagnosed with asthma after moving from Bangladesh to Spain and identified as having mild asthma. She then relocated from Spain to England. Although she mentioned that she does not exercise regularly, Maryam spoke about using gym equipment at her home. She was unable to identify her asthma status prior to the interview. She stated that she has been prescribed a preventer and reliever inhaler to treat her asthma.

Lubna Female Age: 19	Bangladeshi	Budesonide/formoterol fumarate dehydrate (preventer inhaler, known as Symbicort turbohaler) Salbutamol (reliever inhaler) BTS step (dose dependent): 2	Vigorous exercise Runs regularly (up to 5x a week for 1 hour)	A university student (at the time of interview 1 & 2). Lubna was diagnosed with asthma in childhood and identified as having intermittent asthma. She has been prescribed a preventer and reliever inhaler to treat her asthma. Lubna mentioned that she runs regularly up to five times a week and takes part in half marathons and marathons. She also stated that she is regularly active and tries to attend the gym often.
Dhaya Female Age: 20	Indian	Beclomethasone (preventer inhaler) Salbutamol BTS step (dose dependent): 1 (due to reclassification)	Moderate (running, hockey 1-2 hours)	A university student (at interview 1). She was diagnosed with asthma in childhood and identified as having intermittent asthma. Although she identified as having intermittent asthma, Dhaya frequently asserted that asthma did not affect her much and that it is relatively dormant in her everyday life.

Indiana Female Age: 21	Mixed – White Asian (Sri-Lankan & English)	Beclomethasone (preventer inhaler) Salbutamol BTS step (dose dependent): 1	Moderate (Walking and going to the gym – 30 mins and/or 1 hour)	Indiana was a university student at interview 1 and an employed graduate at interview 2. She was diagnosed with asthma in childhood and identified as having moderate asthma. During her childhood, she mentioned that she had been prescribed a brown preventative inhaler to treat her asthma. Indiana described herself as White and Sri Lankan and spoke about her two different cultures. She explained that she enjoys walking, attending the gym and has played several different sports, including tennis, badminton, football and swimming.
Priti Female Age: 19	Sri Lankan	Fostair (2x a day) (preventer inhaler) (see glossary of terms for more information) Salbutamol BTS step (dose dependent): 3	First interview: Moderate (gym, running) Second interview: Walking	A university student (at the time of both her first and second interviews). She was diagnosed with asthma in her childhood and identified as having mild asthma currently. Priti was the youngest volunteer to take part. She mentioned in her first interview that she used to be a regular exerciser, attending the gym and running regularly. She then experienced an asthma attack which

				she believed was exercise induced. In her second interview, Priti explained that she prefers walking, instead of running. She has been prescribed a preventer inhaler and a reliever inhaler to treat her asthma.
Jamal Male Age: 19	British Pakistani	Purple preventer inhaler (no other details mentioned) Salamol Easi-breathe (reliever inhaler) [see glossary of terms for more information] BTS step (dose dependent): 2	Vigorous exercise (gym, weight training, strength training, cardio exercises)	A university student (at interview 1). Jamal was one of two male participants who took part. He explained that he was diagnosed with asthma soon after he was born and identified as having severe asthma. In his childhood, he was prescribed a brown preventer inhaler to treat his asthma. He is using a purple preventer inhaler (which he believes is stronger than the brown inhaler) and a reliever inhaler to treat his condition. Jamal stated that he exercises regularly at the gym and described experiences of cardio training and weight training in his interview.

Tasneem Female Age: 23	Pakistani	Beclomethasone (preventer inhaler) Salbutamol BTS step (dose dependent): 2	Vigorous exercise (running, football, breakdancing)	A university student (at interview 1). Tasneem was first diagnosed with exercise-induced asthma in childhood. She then began experiencing symptoms of asthma outside of exercise at 13 years old and was subsequently diagnosed with asthma when she was 15 years old. She described herself as having severe asthma in childhood, although identified as having moderate asthma in the interview.

Samina Female Age: 22	Asian - mixed other	Fostair (preventer inhaler) Montelukast at time of interview (see glossary of terms for more information) Salbutamol BTS step: 4 if taking montelukast, according to BTS (2016)	Moderate (Zumba - 1 hour a week)	A university student at interview 1 and an employed graduate at interview 2. She was diagnosed with asthma between the ages of 10-12 and identified as having mild to moderate asthma in the interview. In her childhood, Samina explained that she was not prescribed a preventer inhaler, although she has now been prescribed fostair to treat her asthma. Samina mentioned that she takes part in Zumba once a week for one hour. Prior to the interview, she had suffered a severe asthma attack and was hospitalised. After her hospital stay, Samina was prescribed montelukast tablets to help her recover.
Kalan Male Age: 50's	British Asian	In childhood, a preventer inhaler (no other details mentioned) Currently only salbutamol	Moderate (walking, gym)	Kalan was one of two male participants to take part and works for a charitable organisation. He was diagnosed with asthma in childhood and was prescribed a preventer inhaler. He now has a prescription for a reliever inhaler only.

		BTS step: 1		Kalan identified as having moderate asthma and stated that he attends the gym and enjoys walking in the countryside where pollution is less of an issue. He frequently described how his exercise regimes are commonly affected by the weather.
Enayah Female Age: 47	Pakistani	Becotide (2x a day) (preventer inhaler) [see glossary of terms] Salbutamol BTS step (dose dependent): 2	Moderate (jogging in the park)	Enayah was the final participant to take part. She was diagnosed with asthma in her early 20's after her father passed away and has a family history of asthma. She identified as having moderate and exercise induced asthma in the interview. Enayah stated that she does not currently take part in regular exercise, but that she used to enjoy jogging outside in the park next to her home. She had experienced an asthma attack before the interview and this meant that her health had deteriorated and affected her ability to exercise. She has been prescribed a preventer and reliever inhaler to treat her asthma.

Table 7. Table of participants (Pseudonyms have been used to maintain confidentiality).

The chapter now turns to the qualitative methods employed in the current research to achieve the aim and objectives of this study.

4.5 Methods of data collection

In the current research, data was collected using semi-structured interviews (see section 4.5.1). The current research explored participants' biographies and their lived experiences of asthma over a period of time (12 to 18 months), providing a longitudinal dimension to this project. This research thus investigated participants' life course with asthma and their current experiences with asthma. First, one to one interviews were conducted to gain an insight into participants' experiences with asthma, sport and/or exercise and their South Asian culture. After approximately 6 months-1 year after the first interview, follow-up interviews were conducted. A discussion about the use of face-to-face interviews is presented below.

4.5.1 Interviews

Interviews have been considered as a powerful and flexible tool used in qualitative research to capture (albeit partially as researchers cannot fully capture) the voices of those who might be underrepresented in research and different ways people create meaning of their lifeworld and experiences (Daher et al., 2017). Interviewing is a social and active process where the researcher and participant act as co-constructors of knowledge (Yates, 2013). Presser and Sandberg (2015) proposed that stories are fundamental to human existence. Interviews are considered to be particularly useful for healthcare, as they can generate information about patient experiences related to their illness and health beliefs (Mitchell, 2015). According to Mitchell (2015), seeking to understand the patient's experiences through their own words and perspective may help researchers understand how or why patients choose to engage in specific behaviours, and how the illness affects their personal and social worlds. In the case of the current research, each interview helped provide an insight into the participant's personal and social world. Participants articulated their experiences of their symptoms of asthma, their treatment behaviour and their embodied experiences of participating in exercise and/or sport with asthma.

Brinkmann and Kvale (2015) offered two distinct metaphors of interviewer – a miner and a traveller. The miner aligns with positivistic epistemologies and understands knowledge as 'buried metal', making the interviewer-miner someone who would like to discover the treasured,

uncontaminated metal underneath the surface, digging out nuggets of information from their participants' experiences without being subjective (Brinkmann & Kvale, 2015). The traveller on the other hand, aligns with interpretivist epistemologies and is someone who is on a journey or a quest to find stories to be told on their return (Brinkmann & Kvale, 2015). The interviewer-traveller will meet and converse with people they encounter on their journey, roaming freely, asking questions and encouraging people to tell their stories along the way (Brinkmann & Kvale, 2015). Meaning making in the interviewer-traveller's case unfolds by the interviewer-traveller's interpretations of the participants' stories, which can lead to the interviewer-traveller reflecting and adopting new ways of understanding (Brinkmann & Kvale, 2015). The interviewer-traveller approach was adopted in the current study, in line with the interpretivist approach guiding the research. The aim is to investigate the essences of the experience being recalled and understand social phenomena from the actors' perspectives (Brinkmann & Kvale, 2015). Consistent with Brinkmann and Kvale's (2015) approach, I attempted to shift the interview away from sequences that were primarily descriptive, to those which were more analytic or evaluative in search of the meaning of the experience, aligning with the interpretivist approach.

Semi-structured interviews were utilised as the main method of data collection and were dyadic with all 14 participants. Semi-structured interviews involved producing a series of open-ended questions via a flexible interview schedule based on topic areas which provided opportunities for the researcher to follow-up on any areas of interest as perceived by the interviewee, rather than predetermining those areas of interest (Harvey-Jordan & Long, 2001). In the current research, the interview was semi-structured in nature but open to the everyday flow of a conversation (Kvale & Brinkmann, 2009). The main advantage of an open flow approach was that it allowed the participant to speak freely about what they believed was significant to the phenomena being investigated. This is in contrast to structured questions intended to find something specific about the phenomena and restrict the participant to one possible answer (Ezzy, 2002). For example, Jamal spoke about smoking with asthma and although he experienced a recurrence of asthma symptoms when he smoked, he considered the act of smoking to be an important part of his lifestyle. He spoke in length about why he smokes, how he smokes, and how this affects his experiences with asthma. Although, this was not specifically about sport or exercise, or culture, it might have been perceived as important to his personal and social world with asthma. The meaning of smoking and asthma was then interpreted and analysed, and smoking was deemed to be important to his lifeworld because it involved a social aspect and helped him belong to a

group.

The example of Jamal's interview has demonstrated that semi-structured interviews can be used to seek meaning, and I was able to interpret the meanings of what was mentioned, as well as how it was mentioned. According to Flick (2014), semi-structured interviews use broad-ranging questions and are asked in a specific manner to support the growth of a conversation. When used, Flick (2014) explained that the participant's experiences can be articulated and explored clearly, via

the use of effective prompts which facilitate the dialogue. In line with this, the interviews in the current research began with an invitation to describe in as much detail as possible how it felt to have asthma: "*Tell me about your asthma?*", and I approached the interviews as dialogues, rather than a structured schedule of questions, to collect as much insight as possible (see Table 9, p. 124, for the interview schedule). This interview style allowed me a degree of flexibility and was partially participant directed (Broom, 2005). In essence, the participants were free to consider topics that were introduced through the interview schedule (Ezzy, 2002).

According to Brinkmann and Kvale (2015), when seeking meaning, researchers can use a layperson's understanding of body language to understand how types of involuntary expression by the participant might be important to the experience in question. Papas (2015, as cited in Dowling, online, 2015) explained:

> *"Involuntary body language is considered by many to be the most honest form of human expression because it is mainly an innate reaction or affirmation of what the person is really thinking and feeling. The lips may say 'Yes' or 'That makes sense to me,' while the jaw is clenched or their posture turns away from the speaker, both signs of 'No' or 'I disagree.'"*

In line with Papas's (2015, as cited in Dowling, online, 2015) suggestions and using a layperson's understanding of body language, I attempted to note down the participant's facial expressions whilst the interviews were taking place. However, I noticed that my attention was directed towards the participant articulating their experiences and found it challenging to simultaneously attend to both their verbal language and their involuntary body language. Instead, I chose to reflect on each participant interview directly after when the interview was completed, reflecting on any bodily movements or facial expressions I had noted during the interviews.

Questions were asked about the participant's understanding and experiences to provide an insight of their experiences of asthma, exercise, sport, and South Asian culture. A semi-structured interview aimed to understand prominent themes as lived and perceived through the participant's own perspectives (Finlay, 2011). In line with an interpretivist approach, interviews in this sense are not merely treated as information to be added to basic quantitative scientific facts, but as a gateway to people's experience of their lived world (Brinkmann & Kvale, 2015). Below is an extract demonstrating how I tried to shift the participant away from describing the experience to the meaning of the experience. Here, I offered Nafisa the opportunity to clarify what she meant by 'being an asthmatic'.

> Zainab: "*I was just wondering what does that mean… 'I'll still be an asthmatic', what were you linking that to?"*
>
> Nafisa: "*…I practically am still an asthmatic I didn't realise I didn't think I was cos obviously I'd had a good 8 well 21 to now… how many years… so… 14 years I considered myself to be no"*

I interpreted the meaning of this. Nafisa explained that because of the fluctuating nature of asthma, her identity as an 'asthmatic' was not pertinent when her symptoms had subsided for a prolonged period of time. When she experienced symptoms, she resorted back to this identity as an 'asthmatic', a 'self' that she did not expect to turn back to. Her identity remained in flux, dependent on her body's physical state (see section 5.2 for further discussion).

4.5.2 Telephone and Skype interviews

Telephone interviews via Skype were used to complete two of the follow up interviews for ease of access and convenience (Opdenakker, 2006). I had access to a recording system, which recorded the telephone interviews on a computer, and I did not encounter any problems with this. I did, however, encounter connectivity problems during video call interviews via Skype. The limitations involved with telephone interviewing are discussed in further detail in chapter Seven (see section 7.6).

4.6 Interview guide

An interview topic guide (see Appendix 2) was developed based on an in-depth inquiry of previous literature (e.g., research by Griffiths et al., 2001; Hussein & Partridge, 2002). The first interview with Reena was treated as a pilot interview. The aim of the pilot interview was to

ensure that the interview schedule was understandable, clear and culturally expressive, as recommended by Dyson and Brown (2006). The pilot interview also helped me to re-draft the interview schedule by developing or omitting questions. This was completed to help ensure that coverage of key issues was addressed. For example, I chose to ask Reena: *"…what about some of your triggers?".* This question seemed to be mainly related to a description of the participant's experiences. Once I had reflected on this, I became aware that asthma triggers were not a standalone aspect of asthma, and that the topic of triggers can be integrated into other prominent experiences. For example, the weather was a trigger for some participants and was pertinent to their sporting and/or exercising experiences because it often directly affected their ability to exercise or participate in sport.

Commensurate with the purpose of semi-structured interviews and an interpretivist interviewing process, an open 'go with the flow' approach was embraced within the general structure of the interview schedule (see Table 8 overleaf, p. 124, for examples). This allowed new areas of interests to develop, and after consideration, new questions were added to the interview guide. This was particularly relevant when exploring the meaning of South Asian culture and cultural identity. The final semi-structured interview topic guide was used to inform the dialogue in the interviews, following an evaluation of the pilot study. The final interview guide has been presented below in Table 9 (see p. 124, overleaf).

I transcribed verbatim the first corpus of interviews. In addition to the spoken words, I included some non-verbal cues (e.g., silences and facial expressions) (see section 4.5.1 for a discussion about body language in interviews) and emotional features (e.g., coughs & sighs) into the transcribed accounts (Wellard & McKenna, 2001; Halcomb & Davidson, 2006). The process of verbatim transcription allowed me to immerse myself in the data corpus and was necessary to acquire a feeling for the experience of living with asthma. The process of immersion involved becoming more aware of the lifeworld of each participant (Burnard, 1991). Thus, verbatim transcription of each individual interview helped me to understand more about my participants' thoughts and feelings towards different aspects of their lives, for example, living with asthma, making sense of their illness, their sporting and/or exercising experiences and their cultural identity.

Reena:	*" …just cos back home they wouldn't have any sorts of remedies other than the natural ones… the other one was ginger just root ginger boiled… just drink it"*
Zainab:	*"Oh okay…"* [Reena laughs]
Reena:	*"…so it's all very traditional… but they do work"*
Zainab:	*"it's quite interesting that you run five times a week can you explain more about that?"*
Lubna:	*"I tend to do about… six miles… I tend to do… marathons… half marathons and marathons so I…did cross country… when I was a lot younger and then when I sort of started leaving school… I just ran because I like running… I just find it quite pleasurable"* [Lubna smiles]
Zainab:	*"…what types of exercise do you do?"*
Samina:	*"…my exercise tolerance has dropped… since my attack… I struggle to go up a flight of stairs which I'm kind of trying to improve because… you know in baby steps…"*
Zainab:	*"…how do you feel when you're exercising then?"*
Samina:	*"I feel happy [Samina laughs] I feel good, it just takes my mind off everything"*

Table 8. Examples of an open 'go with the flow' approach.

Each interview was tailored to respond to previous answers (Brinkmann & Kvale, 2015). With regard to the number of questions during the interviews, Smith, Flowers and Larkin (2009, p. 60) indicated that *"…ten to eleven open ended questions will occupy approximately 45-90 minutes of conversation, depending on the topic".* Consistent with this, ten open-ended questions were developed, alongside several prompts (see Table 9, p. 124, for the final interview schedule).

Semi-structured interview guide

Questions:

Can you tell me about yourself?

(History of asthma/diagnosis/hospitalisations)

Tell me about your experiences with asthma

(Childhood/adolescent/adulthood experiences)

Can you tell me about what treatments you use?

(*Adherence/ compliance/regular medication/other treatment options)*

Can you tell me about exercise/sports and asthma? Your experiences?

(Type of sports and activities/intensity level/duration)

Describe an asthma attack *(emotions/behaviours)*

Describe asthma in own words *(based on own individual experiences)*

[revised question] Can you tell me how it feels to be South Asian?

[revised question] What does being South Asian mean to you?

Main themes:

Sporting lifestyle

(Sports/activities/barriers)

Triggers

(Environmental/allergies/exercise)

Managing asthma and triggers

(Doctor/healthcare nurse/parents/siblings)

Cultural community

(Barriers/norms & values/behaviours/thoughts)

Religious community *(Barriers/behaviours/thoughts/beliefs)* **Prompts:** *"That's interesting, could you tell me a little more about that?"* *"I see, can you expand on that?"* *"That's interesting, I would like to hear more about that"* *"How do you feel when that is happening?"* *"Why's that?"* *"What happened?"* *"How did that happen?"* *"Can you talk me through that experience please"* *"Is it okay to talk more about that?"*

Table 9. Final interview schedule.

As a qualitative researcher, I understand that I can influence the collection and also the selection and interpretation of data. Finlay (2014) stated that our behaviour can have an impact on participants' responses and attitudes, thereby influencing the direction of the findings. In order to lay claim to the validity and trustworthiness of qualitative research, in my case undertaken by interviews, it was necessary for me to identify the subjective and intersubjective aspects of my research and how they influenced the research. I now discuss the ways in which I used a reflexive approach within my research.

4.7 Reflexivity

This section focuses on my reflective deliberations; an integral component of good quality experiential qualitative research (Langdridge, 2007; Finlay, 2008; Shaw, 2010). It is also essential to studies which employ IPA (Shaw, 2010).

Finlay (2014) proposed that reflexivity or continuous reflexivity can be used as a tool to identify types of reflexive aspects in research, such as our own presumptions about the data. Here, the researcher is engaged in a continual process of self-awareness and it is where subjectivity can be converted from a problem to an opportunity (Finlay, 2014). Some examples of subjectivities can relate to our own judgements and prejudices of the research or the data itself (Payne & Payne, 2004; Williams, 2016). Instead of viewing my subjectivities as a problem, I chose to acknowledge them and note them down to understand how they might have been impacting my research. For example, I engaged in a continual process of reflexivity using various strategies including monthly discussions with my supervisors and completing a reflexive diary (see Appendix 12 & 13), which are discussed below to help make explicit my assumptions and biases towards the topics under investigation.

First, I used a reflexive diary as an opportunity to bracket my assumptions, biases and judgements allowing me to enter the next interview in a different way. Bracketing[11] is a method used in qualitative research to lessen the potentially deleterious effects of the researcher's preconceptions, which may influence the research process (Tufford & Newman, 2012, p. 2). The role of bracketing is controversial for some data analysis techniques such as IPA (see sections 4.10). For example, IPA acknowledges the role of interpretation and encourages the researcher to be interpretative during analysis (Biggerstaff & Thompson, 2008). Thus, the researcher needs to bracket pre-understandings and simultaneously use these pre-understandings as a source of insight (Finlay, 2008). According to Biggerstaff and Thompson (2008), this is one of the reasons why IPA researchers keep a reflexive diary and record details about any emergent interpretations or assumptions which might taint the research process. Tainting in this context referred to the presumptions I had about asthma, sport, exercise and South Asian culture, and how these pre-judgements influenced the data analysis, for example when I presumed to understand what the participants' intended based on my own conjectures about asthma. To mitigate these presumptions from influencing the research process, I chose to make note of any suppositions about the data and spoke to my supervisors about these potential assumptions.

[11] Bracketing, from a sociological perspective, is impossible to employ 'fully' (Allen-Collinson, 2014). Therefore, bracketing in this research was used as an ongoing and continuous reflexive process, where I made note of my assumptions.

By continually speaking to someone who had not conducted the interviews and who had a stronger detachment from the participants, I was able to understand whether I was presuming too much about the data. For example, exploring culture was one of the most difficult aspects of my research because I am from the same background. I identify as South Asian, and many of the cultural aspects discussed by my participants were native to my own understanding about South Asian cultures. I understood my own background and may have assumed it was understood by others who were not part of the same culture. I also presumed that some aspects of my culture, such as homeopathic medicine, was not significant in this research because it was widely practised by people in my culture. I, therefore, believed it was not something distinctive. This was when my supervisors were able to make me aware of the presumptions I was making about South Asian traditions and culture, which helped me to reflect and understand how a person's tradition and culture may be embedded in their identity and may be integral to their way of life. Here, I refer to an example from one of my participants (Reena), who described how important it was for her to stay connected to her traditional rules which influenced the way she lived.

Reena: "*You got to stick to traditions nowadays people don't do tradition… I didn't let my babies out of the house for the first five weeks… I didn't leave the house I didn't expose them to anything they didn't need to be exposed to for the first five weeks… I didn't use any wipes baby wipes, I always used cotton wool and water up until they were good for you… I stick to those rules… traditionally they've been in our… rules for a reason… generations*" [Interview 1]

The various challenges and demands of the research were at times difficult to manage; one of the key issues was my insider perspective as someone who identifies as South Asian female with asthma who exercises regularly. I sought to manage these challenges by keeping a reflexive diary, where I would detail my experiences of each interview and my experience of recruiting participants for this study (see Table 10, p. 128 for examples).

Entry 1 *"I had my first two interviews today with Reena and Nafisa. I had contacted them beforehand via telephone and Facebook and managed to interview them as soon as possible. They were both lovely and very talkative about their asthma and experiences. Reena was my first interview and I had treated her interview as a mini pilot, it ran over slightly (about 15 minutes) but I ended up with a lot of data. I feel much more confident going into my other interviews."*	***Entry 1*** *"I visited an event today to try and recruit some participants. It was held at a temple in Leicester. It was an event about diabetes so I figured a lot of people would turn up, about 35 people turned up but unfortunately none of them fitted my sampling criteria. One person did pick up a leaflet and mentioned his daughter had asthma but unfortunately no one has contacted me."*
Entry 2 *"Today, I visited Aisha; a very friendly woman who kindly participated in the interview. It was a fairly good interview, I felt as though Aisha wanted to talk more about her job and was treating me like a counsellor rather than speaking about her asthma. I did have to slightly nudge the conversation so that she would refer back to her asthma instead."*	***Entry 2*** *"I asked if I could use the RPS forum to get more volunteers for my research. I was successful and it proved effective, as I got nearly 10 people signing up. Unfortunately, some of them did not turn up. I did manage to get about 4 interested parties in the end."*
Entry 3 *"Today, I interviewed a friend of a family member and I think the interview went really well. She was really open and honest and spoke a lot about the embodiment of asthma which helped! I think I came across as confident in the interview."*	***Entry 3*** *"I had some acquaintances who volunteered to take part in the interview, which I was really thankful for."*

Table 10. Examples of interview experiences and recruitment experiences.

Along with regularly conversing with my supervisors, I reflected on my personal issues and experiences during my PhD. I noted these down in a separate reflexive diary, and included comments about stress, taking care of myself during difficult times, and managing my time effectively. I engaged in Brackenbridge's (1999) self-management framework to help me reflect on these issues. In this framework, Brackenbridge (1999) considered the importance of researcher self-care, which involves coping with stress and taking care of the personal and scientific self. I pursued a reflexive approach to enhance the credibility and validity of my research, as Finlay (2014) suggested. In line with

Brackenbridge's (1999) framework, I used the reflexive process to reflect and deliberate on my experiences of coping with stress, the feeling of constant anxiety related to the time constraints of the PhD process and trying to manage a work-life balance. Following the advice of Brackenbridge (1999) in taking care of the personal and scientific self, I kept a diary of my experiences with asthma and exercise. Each reflective diary extract helped my research journey as it allowed me to reflect on the issues present at the time, either in my work or outside of work. By noting these issues down during the course of my PhD, I learned, in essence, how to reflect by making myself aware of my own lifeworld and how I was feeling throughout the duration of my PhD. It helped me become cognisant of concerns (e.g., stress) and helped me to address these problems promptly. I have provided an example of this from my research diary. The example was in reference to coping with stress and taking care of myself, particularly during the analysis stage:

> *"I'm tired. I am interested but I need a break, a refresh. Maybe then my mind will awaken, and I'll have my light bulb moment."* [Diary extract 10]

Reflecting on these moments helped solidify what I needed most in these challenging times, for example when I felt stressed and fatigued. This was important because it helped clarify how I was feeling. Having a reflexive diary for these moments also linked with Brackenbridge's (1999) argument of looking after the personal self. For example, it was important to reflect on what had been causing me frustration because it helped me to understand why I was feeling stressed and enabled me to find a resolution. I needed a break and writing these issues down weekly helped me to embrace these challenges, rather than let them exhaust me. This strategy proved effective as I kept on schedule during my PhD and this method helped rejuvenate my motivation to complete my studies instead of deterring me any further. Continuous reflection and a constant stream of notes about these issues helped me to tackle some of these matters by trying to find a solution. Being reflective helped me understand the PhD process; I needed to act to address any issues I was having. I investigated the sources of my stress and sought to diminish this feeling. I realised I was worried and anxious about my data collection. My data collection was slower than anticipated at times and the anxiety of not knowing whether or not I would be able to recruit participants for my research seemed to add to an upheaval of stress. I sought to address this issue by looking at other options that I could use to facilitate efficient data collection using telephone and Skype interviews. I also looked at other methods of data collection such as diaries, to add to my data corpus. After a constant worry about my first attempt at analysis, I realised I needed to analyse and read the transcripts many more times to gain a deeper understanding about my participants' attitudes and

views towards asthma, sport, exercise and culture, and the meaning they attached to each and every experience. This reflective practice helped me to learn through experience and gain a real insight about how to control and improve my situation (see Cox, 2005). Next, as part of a reflexive approach towards my research, I discuss the challenges and demands of the research journey and refer to excerpts from my reflexive diary to instantiate these challenges.

4.7.1 Challenges and demands within qualitative inquiry

Several researchers have previously acknowledged the challenges posed when undertaking qualitative research (see Ezzy, 2002; Johnson & Clarke, 2003; Campbell et al., 2010; Campbell, 2013). Some of the challenges identified included establishing rapport, developing friendships, maintaining boundaries and reflexivity (Ceglowski, 2000; Rager, 2005; Dickson-Swift et al., 2007; Liamputtong & Ezzy, 2013). These issues are generally specific to qualitative research and are often emphasised when investigating sensitive topics such as chronic illness (McCosker, Barnard & Gerber, 2010). An excerpt from my reflexive diary below shows how the interview process became a learning experience.

> *"I didn't really have to speak much to be honest, they were both very frank and open in discussion. The interviews were both treated as a conversation. I wanted it to feel like a conversation because I feel it makes the participants feel more at ease and helps them open up that little bit more."*
> [Diary extract 1]

I started the interview by asking questions and after some time, I grasped that I did not need to ask specific questions. The participants were open and willing to speak about all of the topics on my interview schedule. As the interview began to flow between us, I realised that I wanted to treat the interviews as a conversation between two people who were interested in asthma and sport and exercise. I tried to be friendly in approach and engaged in conversation about other topics other than asthma. I believed this helped build rapport and trust, which allowed participants to speak freely, particularly when they spoke about complicated issues such as treatment adherence. Some participants spoke about being non-adherent to their treatment regimens and were fearful that disclosing this in the interview would 'get them into trouble' with their HCPs. I assured them that I was independent from the healthcare system and that the purpose of the interview was to understand their experiences and not to make any judgements about adherence or compliance issues.

4.7.2 Self-disclosure

I begin with the issue of self-disclosure. I mention this first specifically because of my position as a South Asian researcher with asthma, who regularly exercises. I often felt I influenced the answers given by some participants. For example, some participants wanted to know how I felt as someone who experienced asthma and some of the participants spoke in a way that implied I understood exactly what they had experienced.

When I first began to collect data, I decided to inform some of the participants that I too had asthma. I disclosed my asthma status to eight participants (Nafisa, Reena, Enayah, Faheema, Samina, Maryam, Indiana & Kalan). I initially did this thinking that it would create a rapport between me and my participants, but I underestimated the influence that I may have had on the participants' answers. Initially, the disclosure on my part that I have asthma went well. The interview was treated as an open dialogue, between two people who experience the symptoms of asthma and understood the possible impact of living with the condition. The participants spoke in greater depth, describing for example how an asthma attack was experienced. Although, subsequently those who knew tended to use this as confirmation that I knew exactly what they were talking about or used it as a comparison to their own asthma in efforts to minimise the severity of their condition (see Table 11, pp. 131-132, for examples of my self-disclosure in some of the interviews).

I decided to conceal my asthma status from the remaining six participants (Priti, Tasneem, Lubna, Jamal, Indiana & Aisha). Participants who had not known my asthma status responded to questions in less depth, whereas the eight that knew of my asthma status appeared to respond to some questions in greater depth.

Maryam:	*"…where are you from?"*
Zainab:	*"Me?"*
Maryam:	*"Yeah… your… ethnicity"*
Zainab:	*"Oh… I'm Indian"*
Maryam:	*"…it <u>happens</u> in… our culture basically… they don't see as much of… good"*

Reena:	*"…I need to say to stay away… otherwise they're gonna set me off"*
Zainab:	*"Yeah… that's good I wish I could do that"*
Reena:	*"Yeah… I'm a lot older than you… sometimes it comes with confidence and experiences"*
Zainab:	*"Yeah I'm labelled as the asthma baby"*
Nafisa:	*"[Nafisa tuts] even now?"*
Zainab:	*"Yeah"*
Nafisa:	*"that is awful"*
Zainab:	*"I know"*
Nafisa:	*"That is horrific no thankfully no one's ever said to me"*

Table 11. Examples of self-disclosure in interviews.

I was aware that my self-disclosure about my own experiences with asthma potentially made me prejudiced to their experiences, for example, I understood how it felt to experience an asthma attack and the participants also assumed I understood this. I noted this down in my reflexive diary. This may have limited their depth of explanation and description of some of their experiences.

Indiana:	*"I don't really know how to explain it [said in whispered tone] obviously you know cos you have it"* [Interview 1]
Maryam:	"*I never had asthma attack how about you did you have it?"*
Zainab:	"*Yeah*"
Maryam:	*"my perspective is in between… I don't experience an asthma attack but you did for you it's gonna be horrible thing but for me it's not that bad cos I manage it and…it's under control".*

Table 12. Examples of interviews with participants who knew about my asthma.

When participants wanted to know about my own experiences with asthma, I felt obliged to answer. The participants, it seemed, felt more at ease during the interview and were willing to speak about other experiences and stories about asthma, but unfortunately, I stopped the recording and was not able to capture this data. On reflection, I believed that when I mentally prepared myself to be open about discussing my asthma, I felt the process of the interview was easier. This was because I was able to connect almost instantly with the participant. The interview became an opportunity for me and my participant to speak about issues that other people might not understand or appreciate in the same way as someone with asthma might do. It seemed that by disclosing my asthma, some participants may have

believed that they could trust me with their experiences because they may have thought that I could understand their identity as someone with asthma.

Charmaz (1991) noted that in order for researchers to understand their participant's experiences, they are required to develop a level of trust with their participants. Liamputtong and Ezzy (2005) suggested that by immersing ourselves in the research process and engaging in self- disclosure, we can help participants to feel more at ease about disclosing their own experiences. For example, I sometimes spoke about my own experiences of asthma to help my participants feel comfortable. I mentioned how I felt when I experienced an asthma attack and my experiences of stigmatisation. This helped me feel as though we were part of a group, as people who were interested in the everyday lives of people with asthma. Although, I am aware that I may have influenced some of my participants responses in my research, Charmaz (1991) argued that we can never know the extent that self-disclosure can have on our participants responses.

4.7.3 Forming relationships with participants

I believe it would be advantageous to state my position here. Guided by an interpretivist approach and a search for meaning, I chose to utilise a 'friendship as method approach' (Tillmann-Healy, 2003). This approach was used to try and get to know my participants in a meaningful way. Friendship as method builds on previous established qualitative approaches and is based on interpretivist principles (Tillmann-Healy, 2003). According to Tillmann-Healy (2003), friendship is related to being in the world with other individuals. Rawlins (2008) described it as an interpersonal bond between people defined by the continuous engagement of a discussion of ideas and tensions. Tillmann-Healy (2003) suggested that friendship as a method in qualitative research actively encourages and disrupts the power imbalance between the researcher and the participant. In doing so, it may diminish the hierarchical separation between the two through *"…the use of dialogue, relationships, and an ethics of caring which offer expressiveness, empathy and emotion"* (Tillmann- Healy, 2003, p. 6; Owton, 2017), towards an *"…epistemology of empowerment rather than colonisation"* (Hill-Collins, 2008, p. 229). Through what Tillmann-Healy (2003, p. 6) termed "*authentic engagement*", the lines between the researcher and participant remain blurred, enabling each to investigate the multifaceted nature of both self and other. In this way, researchers are not *"speaking for"* the participants in our research but getting to know others in meaningful ways (Tillmann-Healy, 2003, p. 6). It is unlikely that a lasting friendship between the researcher and every participant who is involved in the research process will develop, therefore Owton and Allen- Collinson (2014) have suggested that it is important to not mislead participants into thinking

this. Instead, participants should be made aware that the relationship between the researcher and participant is one that is professional and should remain so during the research process. This, however, seems paradoxical, where the researcher must remain professional, and at the same time, foster a friendship-type relationship with the participant.

Tillmann-Healy (2003) argued that researchers do not need to adopt the 'whole vision' to benefit from this specific type of method. Moving towards friendship in research may allude to turning off the tape recorder, speaking with them casually before and after the interview and treating them as we would friends; with mutual respect and understanding for each other (Tillmann-Healy, 2003). Thus, following Tillmann-Healy's advice (2003), I adopted an approach that supports the concept of friendship, one that was characterised by a caring and respectful bond between two individuals (Policarpo, 2015). I approached participants with a desire for mutual respect, visited some of the participants at their houses, joined in with meal preparation for one participant, chatted via Facebook with others and engaged in fruitful conversations with some participants. Although, the traditional practice of data gathering involves speaking to each other with respect and care, friendship as method involves both collecting data (e.g., via interviews) and trying to build friendships with participants by investing more of ourselves in the participant's interpersonal and emotional wellbeing (Tillmann-Healy, 2003). In this way, we are adding emotional and relational layers to our intellectual pursuits (Tillmann-Healy, 2003).

As my research progressed, I discovered that friendship seemed to improve my research relationships. At first, I had not formally met some of the participants and there was an unease and discomfort. After the first interview, I was able to speak to all of my participants in a comfortable conversational way and about other aspects of our lives, instead of focusing on the research itself. There were times when I found it difficult to negotiate the role of researcher/type-friend (Tillmann- Healy, 2003), particularly when I encountered emotional challenges in some of the interviews and when participants spoke about their emotional state regarding asthma. For example, two of the participants were concerned about what they had said to me during the interview and were worried about data confidentiality. I quickly found myself reiterating that the interview was confidential, yet I was left with concerns for them after the interview. In addition, I informed them after the interview that they were entitled to delete parts of their data or withdraw from the study altogether, although they did not do so.

I also knew some of the participants beforehand, which may have further blurred the relationship between researcher/type-friend (Tillmann-Healy, 2003). According to Tillmann-Healy (2003) and Ellis (2007), ongoing relationships can make loyalties much more difficult to navigate in the research process. I

was playing a dual role of a researcher/type-friend and I was continuously trying to negotiate how I felt as a researcher and how I felt as a friend. I often asked myself how I should react both verbally and non-verbally when participants spoke about sensitive and emotional aspects. Employing friendship as a method was difficult in this situation. Tillmann-Healy (2003) stated that is not unusual to feel more empathetic for participants that are already known to the researcher. At the same time, the participants understood that I cared about them, and that they could trust that I would respect their disclosures by using them in the correct and appropriate way.

4.7.4 Employing an 'ethics of caring'

Similar to Tillmann-Healy's (2003) ethics of caring, other evidence (Leininger, 1981; Dickson-Swift et al., 2007; Noddings, 2013) has asked researchers to act '*human'* and respond to their participants in a caring manner. Leininger (1981) identified several behaviours that can be perceived as caring in the research process. I engaged in exhibiting the following behaviours as identified by Leininger (1981): compassion; concern; empathy; interest; and trust. These behaviours were initiated to provide a comfortable and reassuring environment where participants could feel relaxed and content when speaking about issues which are perhaps considered taboo in the South Asian population. For example, I was compassionate and empathetic when some participants spoke about experiencing stigma in their community. I allowed them to speak freely without pressing for more information. I acted with concern when some participants spoke about the psychological impact of asthma. I engaged in all of my interviews with interest by asking further questions and informing interviewees that their experiences were *"very interesting and informative"* and thanking them respectfully at the end. Finally, I created an environment where confidentiality and anonymity were of importance and reassured participants that their information would not be identifiable, but also might well help others with asthma.

It is evident, looking at my experiences, that there are risks involved in qualitative research. For example, I needed to be aware of what I was disclosing to my participants, as well as addressing how I felt when I identified strongly with a participant's experiences. I felt compelled to be reflexive, looking both inward and outward and at the same time, feeling self- conscious about my position in the research process (Taylor et al., 2011). As someone who has been diagnosed with asthma, exercises regularly, and identifies as South Asian, I see myself as an 'insider' (Chesney, 2000) in this research endeavour. Being asthmatic since early childhood has helped me to understand some of the experiences that were described by the participants. Although none of the participants explicitly asked me why I was conducting this research, some were interested to see whether I had asthma. Although I concealed my asthma status from those

who did not ask me, I revealed that I had asthma once the interview was over. This way, all of my participants knew I had asthma, whether they had asked me or not. I wanted them to know why I was interested in this topic area and that they could in some way, trust me with what they had told me during the interviews. The response from participants after discovering why I was interested in research was gratitude. This is because the participants felt that asthma was a condition that, although life threatening, it is sorely misunderstood and undermined. Many of the participants explained that asthma is not taken 'seriously':

> "*I think[12] people do treat asthma too lightly and they really shouldn't, it's quite SERIOUS[13]*" [Lubna]

> "*…people are not aware of how serious it can be, I mean everyone looks and says: 'oh, you only had asthma… it's seen more of like, 'yeah, you've got asthma, you know, get a life, you've got an inhaler'*" [Samina]

> "*…a lot of people don't see asthma as that serious. It's just like, you've got bit of a cough, it's a breathing problem*" [Jamal]

I hope this research helps people to understand just how serious and life-threatening asthma can be. It is also a way to support my participants' voices. These examples exemplify, for me, why asthma-related research requires further attention.

I was very wary of any unintentional bias that I had because I am South Asian. I understood, for example, when my participants spoke about cultural traditions, such as, women cooking and staying at home, or why some women chose not to exercise outside, or why asthma might be stigmatised in South Asian communities, or why some people used traditional remedies like ginger. I almost took these issues for granted until I realised that I needed to separate myself from the data, although not completely, in order to understand the significance of such issues. I did this by speaking to my supervisors, who provided their opinions about the data and helped me to appreciate the data. There are advantages and disadvantages of having an 'insider' position (Merriam et al., 2001). Insiders can potentially get too close to the research area, and they may risk a level of unintentional bias (Merriam et al., 2001). Outsiders, on the other hand, might be more curious about a topic area they are unfamiliar with (Merriam et al., 2001). My position makes it extremely difficult to be an outsider. The insider's weaknesses can act as the outsider's

[12] Words underlined for emphasis.
[13] Capital letters used when participant speaks in a louder tone.

strengths, although this is the same vice versa (Merriam et al., 2001). As Fade (2004) argued, the researcher's influence is essential for interpreting the data and a prior understanding can be used to help make sense of the data.

During the interviews, participants knew that I was South Asian. They had guessed this from my name and the way I looked. Most of them did not know which community I was from, for example, whether I identified as Indian, Pakistani, Bangladeshi etc. One participant was intrigued about my background and asked me during the interview. I told her I identified as Indian, but that I did not really understand my own background. This is because my father was born in Malawi and my mother was born in the UK, so I have never really felt Indian as such. I feel more British but have a South Asian background. On reflection, I believe some of my participants felt this congruence too. One participant was determined that she was not South Asian, yet, she took part in the research. Her parents however had South Asian backgrounds, thus, making her eligible to participate. I realise now that I asked them to label themselves on the basis that it makes it easier for me to understand which community they are referring to in their accounts. Whilst I recognise that knowledge about asthma and sport and exercise remains relatively low in the South Asian population, people's lay and academic knowledge about asthma surprised me. It was common to find that people were uninterested in this topic area, perhaps because they did not believe that it was as important as other issues. As mentioned in chapter Two, the focus tends to be on various other illnesses considered pertinent to South Asians, such as, diabetes (see Lawton et al., 2006; Grace et al., 2008; Keval, 2009) or coronary heart disease (Farooqi et al., 2000; Netto et al., 2007; Sriskantharajah & Kai, 2007).

Being a minority population, I expected the recruitment process to be challenging which it was. As mentioned previously, (see section 2.4), research involving South Asian adults is scarce because South Asians may be reluctant to take part in research (see Rooney et al., 2011). I assumed this was because there is a taboo that continues to exist about participating in research, as well as having a chronic illness, such as asthma. When I asked some family members if they would like to participate, they were unwilling. I am not exactly sure why this is, but it remains an issue. I was also contacted by some South Asian males with asthma who at first, wanted to take part. After contacting them multiple times, they did not reply. I am not sure why. This is the main reason why my research was made up of more females, than males.

Although I fully acknowledge my role as an 'insider', this does not necessarily mean that my closeness to the area would make me disinterested. Instead, it made me quite the opposite. Although I understand

how it feels to have asthma, and to engage in sport and exercise with asthma as a South Asian person, I know that every person with asthma has a different experience. This is what fascinated me, and I maintained my interest in the research throughout. My curiosity encouraged me to learn not only about asthma, sport and exercise, but also about using poems and poetic inquiry as a part of the research process (see section 4.12 for further discussion). I had no prior experience of using the latter before conducting the research.

Moreover, I believe that I underestimated the sense of responsibility that comes with being a PhD researcher. Although I was conscious about the challenges involved when researching a sensitive topic (Dickson-Swift et al., 2007), being aware of the challenges and navigating through them are completely different issues. For instance, analysing my data took much longer than expected. This was because I was constantly worried about whether I had done justice to my participants and their data. I understand that my interpretations of the data are not the only possible interpretations. The findings presented are based on my position and my response to the meaning-making to the study sample. As Finlay (2014) argued, research is co-constructed in context and another researcher might have different interpretations about the data and come to a different conclusion. This is because there is no right or wrong way to interpret qualitative data. Despite this, I am concerned about how my writings would be received, yet still recognise the importance of 'owning one's perspective' as the author (Elliott et al., 1999). The following section details the ethical issues about this research.

4.8 Ethical procedures and considerations

It is of key importance that researchers try and ensure the welfare of participants in their research studies (Mertens, 2014). In order to address a range of ethical considerations, ethical procedures were followed in accordance with DMU's Health and Life Sciences Ethics Committee guidelines, together with those of the British Psychological Society (BPS). The DMU Health and Life Sciences Ethics Committee approved this research (see Appendix 5).

Interviews usually involved topics of sensitivity, which can make the interviews emotionally intense and may cause harm to both the researcher and interviewee (Clarke, 2006). Given the sensitive nature of the current research (which included looking into traumatic life events), it was important to consider emotional risk assessment. According to the BPS's (2018) code of ethics and conduct and the American Psychological Association's (APA) (2017) ethical principles for psychologists and code of conduct, all participants must be able to withdraw at any time without providing a reason and researchers must ensure participants do not experience distress during the

interview. Following these recommendations, participants in the present study were not obliged to speak about or answer anything they felt uncomfortable with and were able to withdraw without providing a reason, although none did so. The participants were advised on withdrawal rights before the interview began. If the participants wanted to withdraw their data, they could do so, as long as they contacted me or my supervisors within 72 hours of the initial data collection. Additionally, participants were able to contact me if they wanted to delete any part of their data, although none chose to do this. When the follow-up interviews were completed, some of the participants were interested in the themes that were emerging from the data corpus and wanted to voice their opinion about them. I reflected on the feelings of the participants and chose to openly speak about some of the themes within the data and record their views during the follow-up interviews.

Informed consent has been extensively examined in qualitative inquiry (Wiles et al., 2008; Allmark et al., 2009). Guillemin and Gillam (2004) endorsed a continual process of consent as part of a reflexive approach to research. Following this recommendation, I adopted a continuous process of confirming consent throughout the interview. For example, I used prompts such as, "…*is it okay to talk more about that?"* to reaffirm the participants' oral consent. Once the participants agreed to take part, both parties negotiated a time and a place for the interview to take place. Before the interviews began, I asked the participants to confirm if they were happy to take part and whether they understood the project's aim and objectives; this acted as oral consent. With regard to practices 'on the ground', each participant was required to sign and date a consent form, which acted as written informed consent, as per the BPS's (2018) code of human research ethics. All ethics information and a blank participant information sheet and consent form have been provided in the appendices (see Appendix 3, 4 & 5). The participants were asked to initial the consent form, as well as sign it to ensure that they had read and understood each of the terms set out on the form. I believed it was necessary to speak about informed consent before and after the interview, which was relevant to an individual's decision to participate and commit to providing their data.

Tilley and Woodthorpe (2011) endorsed the idea of using pseudonyms in qualitative inquiry where possible, to protect anonymity. In line with this, any names that were mentioned were altered using pseudonyms. Direct quotations were also anonymised in the final thesis and any published articles resulting from the research. Ipfohen and Tolick (2018) stated that researchers must attempt to promise confidentiality. According to the Data Protection Act (2018), all personal information must be kept confidential and where desirable, stored in a safe and secure manner.

Therefore, all materials were kept away from signed consent forms in a locked storage unit and will be destroyed towards the end of 2021, 5 years after the collection of data as per DMU's research records retention policy (DMU, online, 2007). Any follow-up interview data was kept strictly anonymous and will also be destroyed towards the end of 2021. The BPS's (2018) code of human research ethics states that interview data must be stored securely. Keeping in line with these anonymity principles, all of the interview data collected including sound files and transcripts, were stored on password protected computers.

Participants were required to provide their name, age, gender, self-described ethnicity, type of asthma and type of exercise and/or sport for analysis purposes (see Appendix 6). I asked participants to record their names because I required this information when contacting them for a follow-up interview. Their name was known only to me, with the exception of two acquaintances who were known to a close family member. The acquaintances informed the family member that they would be taking part. In the final thesis, any distinguishing characteristics that would potentially make the participant's role identifiable was deleted or excluded to protect the participant's anonymity, specifically for those who were known to my family member. I assured all of the participants that pseudonyms would be used to conceal their identity and that of any significant others they may have mentioned during the process. This chapter now moves on to the type of data analysis used for this research.

Reflecting on the advantages of the interpretivist approach led to the adoption of IPA (Smith et al., 1999); an analysis technique that focused on the subjective accounts of UK-resident South Asian adults' experiences with asthma and their exercise and sporting experiences. In selecting this approach, experiential accounts were the main focus as opposed to investigating pre-conceived hypotheses and I was able to use this type of analysis to interpret and understand the participant's account on a meaningful level (Cope, 2005).

4.9 Choosing interpretative phenomenological analysis (IPA)

Smith (2011) explained that IPA emphasises the assembly between embodied experience; *"…a person's talk about that experience and making sense of, and their emotional reaction to that experience"* (p. 15). IPA research, thus, attempts to illuminate a phenomenon and is interested in how a phenomenon reveals experiences as they are lived by the *"…embodied socio-historical situated person"* (Eatough & Smith, 2017, p. 4). Experience in IPA research refers to something which matters to the individual and something of which they have some understanding of and as

IPA researchers, we seek to understand the participants' perspective of the experience (Larkin & Thompson, 2011). Thus, IPA research involves trying to understand the experiences of a specific group of individuals, in this case, UK-resident South Asian adults with asthma who participate in sport and/or exercise. This research aimed to give voice to this particular group of people (Larkin & Thompson, 2011). IPA is based within phenomenology and hermeneutics and aligns itself with personal and subjective accounts of experience as part of its qualitative approach to research (Eatough, 2012). A brief discussion about IPA's epistemological origins as an experiential approach which emphasises the role of the researcher, is provided below.

Husserl's (1970, p. 2) phenomenological intention is to "…*describe the phenomena themselves"* and is understood as a process of "…*stripping away*", as far as one can, any presumptions or judgements the researcher may have about the phenomena being investigated (Eatough & Smith, 2017, p. 3). 'Phenomenological reduction' is a core part of this process, as it provides a way of 'cutting through' these layers of taken-for-grantedness that encircle phenomena via the *epochē,* also sometimes called 'bracketing'. Bracketing enables researchers to arrive at the phenomena's *eidos,* or its core and its 'essential' feature(s) (Allen-Collinson, 2018, as cited in Smith & Sparkes, 2016, pp. 11-13). Husserl (1970, p. 20) stated that the *epochē* allows researchers to stand aside from their existing beliefs in order to return to *"…the things themselves".* This interest links IPA to Heidegger's (1962) work with engagement in phenomenological and experiential research. Heidegger (1962) conceptualised the notion of '*dasein'* as *'being there'*; it has also been termed as *'…being-in-the-world'* (Spinelli, 1989, p. 108). This notion of *'being there'* endorses IPA's acknowledgement of people living in worlds that are socially and historically contingent and contextually bounded (Eatough & Smith, 2017). Merleau-Ponty (1962) further discussed the concept of '*dasein'* and explained that the body is a body-subject, rather than a body- object; the body as individuals experience it and are aware of it is important, as it can provide meaning to the world around them (Meulen & Van Woerkom, 2009). Thus, the phenomenological interest is with the lived body or *'leib'*, rather than a sole focus with the physiological mechanisms of the body (Eatough & Smith, 2017).

One key aspect of IPA is the process of hermeneutics. The term hermeneutics originated from the Greek verb, *'hermēneuein'* or to interpret, and the noun, *'hermēneia'* or interpretation and it is used to *"…make meaning intelligible"* (Grondin, 1994, p. 20). Heidegger (1960, as cited in Eatough & Smith, 2017b, p. 5) and Gadamer (1960, as cited in Eatough & Smith, 2017, p. 5) advocated that *"…to live a life is to interpret*". According to Smith, Flowers & Larkin (2009), when trying to make

sense of the participant's lived experiences, it encompasses close interpretative engagement with the data. In contrast to the descriptive tradition of phenomenological reduction, which asks researchers to rid themselves of all assumptions as far as one can in order to understand the phenomena as it is described, an interpretative phenomenological approach argues that former knowledge is required in order to understand the meaning of phenomena (Willig, 2003). Smith et al. (2009) explained that researchers are involved in a cyclical approach between pre-understanding and understanding, whereby researchers move back and forth in an attempt to understand and interpret the meaning of the phenomena under investigation. Hermeneutic phenomenologists termed this process the "*hermeneutic circle*"; the whole can only be understood via understanding of its parts (Langdridge, 2007, p. 122). According to Koch (1995), a researcher's presuppositions are what helps them to acknowledge the gaps in the research area and to investigate a phenomenon. Thus, the researcher's knowledge guides the research process in a meaningful way (Lopez & Willis, 2004). Interpretive phenomenology works with these assumptions, arguing that presumptions are integral to meaning making (Willig, 2003). IPA's main interest is to attempt to understand a person's experiences and how they make sense of these experiences, instead of the structure of the phenomenon as traditional Husserlian phenomenology would dictate (Eatough & Smith, 2017).

IPA was utilised to try and gain an in-depth perspective of what 'it is like' to experience phenomena, in this case, what 'it is like' to experience exercise and/or sport as a South Asian adult with asthma, resident in the UK. IPA is inductive and is built on tenets of phenomenology, thus making it phenomenologically-inspired (Eatough & Smith, 2017). IPA is often associated with the symbolic interactionist approach (Eatough & Smith, 2017). This means that researchers who utilise IPA often believe that each individual sees and interprets the social world differently (Eatough & Smith, 2017). The way they see and interpret each event in their social world is dependent on their experiences, and thus each event holds meaning (Eatough & Smith, 2017). The researcher is integral to the interpretation of the phenomenon in IPA, as their intention should be to try and capture these meanings and present them in an appropriate manner (Eatough & Smith, 2017). The following section (see section 4.10) explains how this can be achieved and describes the research technique of IPA in detail.

IPA is a qualitative analysis research technique developed by Jonathan Smith (Smith, 1996; 2004; 2007; 2009). IPA is used to provide a voice and to capture and reflect on the claims and concerns of the participants (Smith et al., 2009). An IPA researcher is required to collect detailed first-hand

accounts and offer a phenomenologically-inspired approach to the interpretation of the participant's subjective words (Smith et al., 2009). Applied in this study, IPA was used to develop a fuller, in-depth understanding, of a UK-resident South Asian adult's lived experience of asthma and exercise and/or sport.

IPA consists of three main theoretical principles (Smith et al., 2009). The first principle is concerned with the appreciation one must have for the participant's own perspective of their experiences. It relates to how the participant assimilates elements of their perceptions, judgements, memories, beliefs and attitudes about something into one meaningful experience (Smith et al., 2009). The second principle is about how IPA is deeply committed to exploring each individual's unique and particular experiences (Eatough & Smith, 2008). The final principle relays the interpretative (hermeneutic) element of IPA, rather than a descriptive approach (Smith et al., 2009). According to Smith et al. (2009), IPA encompasses a double hermeneutic: the participants are trying to make sense of their own experiences (the first hermeneutic layer), whilst the researcher is trying to make sense of the participant's experiences during analysis of the data (the second hermeneutic layer). Below, the steps towards successful implementation of IPA (Smith et al., 2009) in the current research is provided.

4.10 IPA data analysis

Smith et al. (2009) proposed that the researcher should read the data multiple times and note down anything of significance in the left-hand margin. In the current research, I did so, reading the transcripts six or seven times in order to gain familiarisation with the data. Each reading has the potential for new insights to appear and should be done with each transcript (Smith et al., 2009). Next, the researcher should return to the beginning of the transcripts and note down in the right-hand margin, emerging theme titles (Smith et al., 2009). At this stage, the notes are used to capture the quality of what is emerging in the transcript and the themes in turn, provide a higher level of abstraction (Smith et al., 2009).

1. The close line-by-line analysis of the experiential claims, concerns, and understandings of each person.
2. The identification of emerging patterns within this experiential material, emphasising convergence and divergence, commonality and nuance, usually for single cases, and then subsequently across multiple cases.
3. The development of a 'dialogue' between the researchers, their coded testimonials, and their social knowledge, about what it might mean for people to have these concerns, in this context leading in turn to the development of an interpretative account.
4. The development of a structure, frame, or Gestalt, which illustrates the relationship between themes.
5. The organisation of all this material in a format which allows for analysed data to be traced back through the process, from initial comments on the transcripts, through initial clustering of thematic development, into the final structure of themes.
6. The use of supervision, collaboration, or audit to help test and develop the coherence and plausibility of the interpretation.
7. The development of a full narrative evidenced by a detailed commentary on data extracts, which takes the reader through the interpretation, usually theme-by-theme, and is often supported by some form of visual guide (a simple structure, table or diagram).
8. Reflection on one's own perceptions, conceptions, and processes.

Table 13. The IPA iterative and inductive analytical cycle (listed in chronological order) (adapted from Smith, Flowers & Larkin, 2009, pp. 79-80).

Step one: Reading and re-reading (Smith, Flowers & Larkin, 2009, p. 82)

The first step of IPA analysis involved *"…actively engaging"* with the data (Smith, 2007, p. 82).

- This involved reading the transcript several times and regularly reflecting on the data in order to enter the 'Lebenswelt' or 'lifeworld' of the participant (Husserl, 1999).

- A close reading of the transcript enabled me to acknowledge and appreciate each participant's experience of asthma, sport and/or exercise and South Asian culture.

Step two: Initial noting (Smith et al., 2009, p. 83)

Step two involved a detailed analysis of the transcript (see Appendix 7). It required an

examination of the semantic content and language (Smith et al., 2009).

- I explored the use of language and semantic content (Smith et al., 2009) by making initial notes on the left-hand side of the transcripts.

- Steps one and two merge in this way in practice, as I started writing notes when I read and re-read the transcripts and then added further explanatory notes and comments during step two.

- Three types of comments are made here: descriptive comments, which describe the experience, linguistic comments, which attends to the words and expressions participants' use, and conceptual comments, which were informed by my knowledge of the literature.

- I also began to note down any presuppositions I had during this stage (Clandinin & Connelly, 1998). Although some (e.g., Smith et al., 2009; Cassidy et al., 2011) have argued that the researcher's former knowledge of the phenomena is required in order to understand more about the investigation, setting aside or bracketing preconceptions of the researcher's basic understandings or 'fore-conceptions' of the phenomena, must be acknowledged during analysis. Therefore, IPA researchers are asked to adopt a *"…sensitive and responsive approach to data collection and analysis…"* (Larkin, Watts & Clifton, 2006, p. 108), which enables the researcher to be aware of his/her preconceptions. This requires the IPA researcher to carefully attend to the data and creates a cyclical process of bracketing; one which requires the researcher to identify presuppositions during each analysis of the data (Smith et al., 2009).

- In order to engage in a cyclical-type process of bracketing (as far as possible), I chose to write down anything which was linked to my previous understanding of the topic. I spoke with my supervisors about these perceived presumptions in order to understand whether or not I had in fact, assumed something about the participant or their experiences. I tried to avoid making conclusions about what the participants were saying or implying, or not saying or implying, by reviewing each transcript several times and writing in a different coloured pen to identify such judgements.

- Smith et al. (2009) explained that the analysis of a person's lived experience is a difficult

but insightful process. This step was carried out seven separate times over the course of three years. In the current research, I found it challenging and very time consuming to complete this type of exploratory analysis throughout a three-year period. At the same time, engaging with the transcript multiple times enabled me to shift from making descriptive comments to exploratory comments which focused on meaning. For example, exploratory comments were recognised as issues that were important to the participant, such as the participation of exercise and/or sport to the value and meaning of exercise and/or sport for UK-resident South Asian adults with asthma.

- Each time analysis was completed, notes were compared to the previous analysis to help develop the understanding of each participant's experiences. I compared notes approximately seven times during the final analysis of the transcripts. This step enabled me to grow closer and more familiar to the transcripts and identify how each participant spoke about their experiences and how they reflected on these aspects.

Step three: Developing emergent themes (Smith et al., 2009, p. 91)

In looking for emergent themes, step three required me to map out the interrelationships and patterns between the exploratory notes of each transcript, whilst also trying to identify emergent themes and the flow of the interview fragments (Smith et al., 2009).

- This step embodies one manifestation of the hermeneutic circle, where the interview transcript becomes a set of parts and then comes together in a new whole at the end of the analysis (Smith et al., 2009). This was particularly difficult to accept, and I found it challenging to give myself a more central role at this stage as it took me further away from the participant.

- At the same time, I was involved in placing myself in the IPA process. Smith et al. (2009) explained that the resulting analysis is the collaborative effort between the participant and researcher. For example, the data and exploratory comments are participant-oriented and the attempts to develop emergent themes is researcher-focused.

- Turning notes into themes involved producing a succinct statement about what was important in the exploratory comments in each transcript. The themes reflected both the participant's original words and my interpretation of the data, illustrating a

collaborative practice of description and interpretation (Smith et al., 2009).

- As part of the reflective process, it is important to consider my position during this stage. As a South Asian person female who has asthma, there were specific themes which seemed salient to me because of my understanding of the issues reiterated by participants. However, I spoke to my supervisors who did not identify as South Asian and one of whom was a healthcare professional, about my relatability to several themes. It is appropriate to state that my background influenced this stage, and I developed themes based on my relatability and knowledge about asthma, sport and/or exercise for South Asian adults, for example, I understood how it feels to be prescribed a preventer inhaler and how my exercise and/or sport level of performance is affected from having asthma, and how my culture as a South Asian Indian influences my attitudes towards pharmacological treatment (see Chapter Five for a detailed discussion).

Step four: Searching for connections across emergent themes (Smith et al., 2009, p. 92)

The analysis of the transcript established several themes and these themes were ordered chronologically. The next step was to try and map out how the themes connected and fitted together (Smith et al., 2009).

- I attempted to chart these connections and moved around some themes, clustering them into related themes.

- To de-clutter the themes, Smith et al. (2009) suggested creating theme tables (see Appendix 8) to cluster the themes and discard those that do not fit well with the research scope. I also developed a theme table for each participant (see Appendix 8 for an example).

Step five: Moving onto the next transcript (Smith et al., 2009, p. 100)

Since there were 24 different transcripts for 14 different participants (14 initial interviews; 7 follow- up interviews; 3 email follow-ups), the next step was to repeat steps one to four of the analytical process.

- It was important to treat each transcript as its own individual case in order to demonstrate its individuality. This meant that I treated each individual transcript separately and followed steps one to four precariously to understand each participant's

lifeworld, commensurate with IPA's commitment to idiography (Smith et al., 2009).

- During this process, Smith et al. (2009) noted that the researcher can potentially be influenced by what they have found in the previous transcript. To resolve this, I attempted to bracket (as far as possible) my assumptions and any ideas I might have had which emerged from the analysis from the previous transcript. Also, new themes appeared within some of the follow-up transcripts.

Step six: Looking for patterns across transcripts

This step involved looking for patterns across the data set.

- I looked at the participants' theme tables (see Appendix 8 for an example), laying them out together and looking across them to discover any connections.

- A list of subordinate themes (see Appendix 9, 10 & 11) was developed, in order to present the themes for the group as a whole. This also helped to establish how each subordinate theme was nested within a super-ordinate theme.

Step seven: Presenting the analysis

Smith et al. (2009) explained that this requires presenting a comprehensive narrative account of the results in a systematic and persuasive way for the reader. This is a critical part of the IPA process.

- The results section of the current IPA study was constituted by a large proportion of transcript extracts and detailed analytic interpretations of these extracts. I chose to use this approach because I wanted to communicate a sense of what the data was like to the reader and offer my interpretation of the data. In essence, I wanted to demonstrate what the data might have meant to the reader (Smith et al., 2009).

- It was the experiences and narrative meanings that were sought in the present study. Since this can be subjected to criticism from other methodologies such as positivistic approaches, a qualitative approach needs to be understood in regard to how it can be judged, so that it can be evaluated appropriately (Smith & Sparkes, 2009).

This leads to the next section (see section 4.11), where I discuss the issue of validity in qualitative research and how it might be evaluated.

4.11 Assessing validity and quality in qualitative research

Smith et al. (2009) argued that there is now considerable discussion about how the quality of qualitative research should be considered. There seems to be an increasing dissatisfaction with the way qualitative research is assessed when it is judged according to the criteria of reliability and validity used in quantitative research (Smith et al., 2009). Generally, judgements about what constitutes scientific research and its quality are often linked to notions of reliability, validity and generalisability of the methodology in question (Smith et al., 2009). IPA studies are not an exception

to these judgements (Smith, 2011; Eatough & Smith, 2017). According to Smith et al. (2009), the validity and quality of qualitative research should be considered more widely and should be evaluated with an appropriate criterion.

In traditional quantitative terms, validity is defined in terms of whether an instrument measures what it is supposed to measure and whether it provides the correct answer (Kirk & Miller, 1986). The search for validity in the positivist epistemological approach is often considered 'a search for the truth' (Kuzmanić, 2009). According to Kuzmanić (2009), if researchers who explore social phenomena use this notion of truth, it would be problematic as it presumes that there is a truth out there that can be accessed via appropriate research methodologies. Kvale (1996) proposed a more theoretical approach to this and focused on the social constructions of validity in interviews. For Kvale (1996), issues of validity in qualitative research and in interviews in particular, are related to the conceptualisations of knowledge and truth, and suggested that there are multiple ways of knowing and multiple truths, as there are interpretations. Therefore, if qualitative inquiry proceeds from this, the validity of such inquiry can be about representing different interpretations of social worlds (Kvale, 1996). In interviews, the truth is considered through the use of dialogue and the human construction of meaning, thus, the quest for absolute knowledge is not appropriate (Kuzmanić, 2009). Drawing on these debates regarding the assessment of validity in qualitative research, a discussion about how IPA studies, including the current research, can be judged is provided. Smith et al. (2009) proposed using the criterion set by Yardley (2000), who suggested four broad principles for judging the quality of qualitative research:

The next section describes how each principle was addressed in the current research. It begins with the first principle, which is sensitivity to context (Yardley, 2000).

4.10.1 Sensitivity to context

According to Yardley (2000), good qualitative studies should demonstrate sensitivity to context. There are several ways this can be acknowledged in an IPA study including, showing gratitude and appreciation for the participants during the interviews and engaging with existing literature to help orient the study (Smith et al., 2009). I chose to demonstrate this principle by working closely with participants in the interview by showing empathy, helping the participants feel comfortable and at ease during the interview, and trying to negotiate the hierarchical power imbalance between the participant and myself as the researcher. For example, I spoke to the participants with respect and care and conversed with them in a friendly way about the details of the research. I also constantly reiterated how appreciative I was for their participation in the research.

Sensitivity to context also continues into the analysis stage of an IPA study (Smith et al., 2009). When researchers are trying to make sense of the participants' experiences, he/she should be sensitive to the data itself and to the raw material (Eatough & Smith, 2017). Smith et al. (2009) suggested that a considerable amount of verbatim transcript extracts should be included to support the argument being made. This aspect was demonstrated when I provided several different transcript excerpts in the findings and discussion chapter (see chapter Five). The addition of different excerpts helped to support my claims, alongside supplementary analytic commentary. This enabled the reader to check my interpretations. The second broad principle, 'commitment and rigour' (Yardley, 2000) is now discussed.

4.10.2 Commitment and rigour

Commitment can be demonstrated by the degree of attentiveness that researchers display to their participants (Smith, Flowers & Larkin, 2009). In an IPA study, the researcher should personally commit and invest themselves in the research process by attending closely to the

participant. I was committed to the participants during the research with whom I treated with care and respect, which appeared to be synonymous with an expression of sensitivity to context (Smith et al., 2009).

Rigour represents the meticulousness and diligence of the study, for example, the suitability of the study sample with regard to the research topic under investigation, the quality of the interviews, and the comprehensiveness of the analysis (Smith et al., 2009). In the current research, conducting a good interview required a considerable amount of attentiveness, along with specific prompts to enable me and the participant to dig deeper. The analysis of each transcript was conducted thoroughly and systematically and treated individually, keeping with IPA's commitment to idiography. In addition, the analysis was comprehensive and sufficiently interpretative, moving from descriptive comments to exploratory comments (see section 4.10) to demonstrate the significance of the themes presented in the findings and discussion chapter (see chapter Five). Next, the third broad principle is considered, 'Transparency and coherence' (Yardley, 2000).

4.10.3 Transparency and coherence

Transparency is about how clearly each stage has been described in the write up of the study (Yardley, 2000). This can include a description of how participants were selected, the development of the interview schedule, or how the interviews were conducted (Smith et al., 2009); all of which have been explained previously (see sections 4.3-4.6). In addition, some of the reflexive aspects of the current research have been discussed in detail (see section 4.7), together with information about the ethical procedures employed in this research (see section 4.8).

According to Yardley (2000), the coherence of a piece of qualitative research is about the way the research presents itself to the reader. Much of this is judged by the reader and so Yardley (2000) suggested that it is important to read the final thesis carefully and to think about whether the reader will understand the final write up. In this research, the final thesis was checked and read thoroughly for any errors and was written to present a coherent argument about UK-resident South Asian adults' experiences of asthma and their exercise and/or sporting experiences. Lastly, the fourth broad principle, impact and importance, is considered.

4.10.4 Impact and importance

Impact and importance relate to whether the research offered something meaningful, important

or valuable to the reader (Yardley, 2000). The current research has provided a unique perspective about UK-resident South Asian adults' experiences of asthma and their exercise and/or sporting experiences, given the dearth of academic literature about the topic. It offered an insight about how they manage asthma, sport and/or exercise, and the cultural conceptions about asthma, sport and exercise from 1st, 2nd and 3rd generation UK-resident South Asian adults. Written using the participant's perspective, this research enabled me to understand more about a UK-resident South Asian adult's sporting livelihood with asthma.

This research aimed to inform academic and clinical practices by identifying and understanding the lived experiences and embodiment of those with asthma, who take part in sport and/or exercise and who identify themselves as UK-resident South Asians. Possible interpretations of asthma, its symptoms, medication and diagnosis, sport and exercise participation, and cultural perspectives can help contribute to the field of asthma and sport research in the UK-resident South Asian cohort.

Once researchers understand these meanings, it can have implications for several issues including treatment regimes, sport and exercise participation rates, cultural influences and how these might vary in different contexts (e.g., during symptom-free periods). Therefore, the current research was approached using a qualitative, interpretivist, phenomenologically-inspired methodology and used

qualitative methods to investigate the subjective meanings that are central to an understanding of a UK-resident South Asian adult's asthma and sporting and/or exercising experiences.

4.12 Representing data using poetry

The participants' experiences also required another more evocative technique to bring to life the experience of asthma for readers. Therefore, some of the data were represented as poetic representations. Poetry as an alternative approach seeks to add the voices of participants to the research and provide different ways to try and understand others' perspectives and experiences (Vincent, 2018). In the current research, it provides a stimulating and evocative approach towards understanding the relationship between asthma and sport and/or exercise. Poetry is arguably different to other qualitative analysis techniques because it condenses language into a relatively short summary, to create a narrative which has the ability to express a powerful and emotionally evocative message for the audience (e.g., Faulkner, 2007; Cousin, 2016; Happel-Parkins & Azim, 2017). Additionally, poetic techniques are flexible and emphasise the emotional and experiential aspects of a

phenomenon, in order to discover new perspectives. According to some scholars (Langer & Furman, 2004; Fenge, Hodges & Cutts, 2016), it showcases a more profound level of insight than other traditional forms of analyses.

I was motivated to represent data in this way because poetic inquiry offers another template of how subjective experiences could be articulated in writing (Gergen & Jones, 2008). Previous work by Owton (2012; 2013; 2017) on White Caucasian adults' descriptions of their asthma and sporting experiences also sparked an interest in me for using poetry. Owton (2012; 2013; 2017) used traditional data analyses in the form of semi-structured interviews, together with arts-based approaches including poetic inquiry and narrative art. Owton's (2012; 2013; 2017) work investigated the experiences of asthma and sporting embodiment and revealed that the asthma and sporting identity was negotiated in different ways. This, however, was conducted solely in a White Caucasian adult sporting population and did not consider ethnic and/or cultural identity or ethnic and/or cultural differences.

Poetic inquiry has not been used in the UK-resident adult sporting and/or exercising South Asian population with asthma. The use of poetic inquiry and/or representation with non-White and/or marginalised groups is less prevalent. Similarly, to Washington (2009), who used poetic inquiry with Black women, this article explores the use of poetic inquiry within the constructs of South Asian culture. According to Washington (2009), a poetic lens offered a unique vantage point to interpret the narratives of Black women in her study sample. In the current research, I aimed to represent my participants' data in ways which emphasised the richness of the South Asian cultural landscape. According to Leavy (2015), poetic inquiry can "…*unsettle stereotypes, challenge dominant ideologies, and include marginalised voices and perspectives"*, through understanding and compassion and by "…*jarring people into seeing and thinking differently"* (p. 24).

4.12.1 Background to poetic inquiry

Carl Leggo, who is considered a pioneer in poetic inquiry explained that *"…the poet is the human scientist"* (Leggo, 2008, p. 165). Leggo (2008, p. 165) further stated that *"…poetry invites us to experiment with language, to create, to know, to engage creatively, and imaginatively with experience"* (Leggo, 2008, p. 165). In order to encourage new ways of investigating social research and bringing these new ways of knowing to expansive audiences, Leavy (2015) suggested that researchers need to be able to think and see

differently.

Creative and artistic representations of data can also produce insights which may not have been previously discoverable with conventional and traditional modes of representation (Owton, 2012; Smith & Sparkes, 2016). According to Butler-Kisber (2018), poetry can appeal to a person's senses and it invites them to different ways of knowing and seeing. If executed well, the poetic representation has the power and the ability to produce redolent and fluid links to the data for the reader and audience (Rapport & Sparkes, 2009). Poetic representation is utilised to inspire different interpretations and permits a greater interpretive liberty, enabling the audience to develop their own interpretations about the data (Rapport & Sparkes, 2009). The audience can then use this to understand how it fits with their own lives (Sparkes et al., 2003; Rapport & Sparkes, 2009). In relation to sport-focused research, Sparkes et al. (2003) argued that it should consider utilising the power of poetry to help the audience to understand more about their own experiences, as well as the experiences of others. In the current research, the poems aimed to demonstrate how a condition often associated with breathlessness and chest tightness is treated and managed during sport and/or exercise in the UK-resident South Asian adult population.

Poetry as a form of representation, relies on word and lyrical invocation and therefore, joins two methods of expression to create an evocative presentation of the data (Hirshfield, 1997; Leavy, 2015). Leavy (2015) explained that poetry is extremely attentive to space, which include breaths and pauses; the latter is analogous to the experience of asthma. Poetry tries to create or "*paint*" (Leavy, 2015, p. 78) a *"feeling picture"* (Leavy, 2015, p. 78) by using words sporadically. In essence, poems carefully place together words, rhythm and space, to produce sensory passages where meaning emerges from the skilful assembly of language and silences (Leavy, 2015). A poem may therefore be considered as a way to evoke and artistically express a fragment of human experience, which aims to push feelings to the forefront (Leavy, 2015). The literature has indicated that poetic inquiry arose in response to what Denzin and Lincoln (2011, p. 3) described as a "…*crisis of representation*". Prendergast and Galvin (2012) described this crisis as a response to research that "…*appropriated, overpowered, fragmented, rendered-over summative or even silenced*" participants' voices (p. 5).

In addition, Eisner (1981) explained how artistic facets within qualitative research could be used to help the reader understand more about the phenomenon under investigation. According to

Eisner (1981), poems are used to bring the reader into the experience, for them to listen deeply, put themselves into the participants' context, and be empathetic to the participants' phenomena. Poetic approaches in the current research, aimed to help the audience experience how it feels to have asthma, and to be a South Asian sporting individual with asthma. Eisner (1997, p. 5) further stated that *"…poetry was invented to say what words can never say. Poetry transcends the limits of language and evokes what cannot be articulated".* In Eisner's (1997) view, although poetry is made up of words, it is about more than words. Although researchers know about asthma, they might be able to understand the dynamic and complex sensory nature of asthma. However, through the use of poems, one might be able to understand how it feels to experience an asthma attack, breathlessness and chest tightness and in some cases, the fear of death. Spiers and Smith (2016) suggested that poetry is about the compilation of words, its structure and its ability to be poignant. It is about the:

> *"…rhythm of the words, rhyme, assonance, alliteration, pitch and tone, which are combined to create a resonance that is more than the sum of its parts"* (Spiers & Smith, 2016, p. 238).

Thus, the structure of a poem is to evoke a "*resonance*" with the reader, in this case, how asthma affects a person's life. Although poetic representation in qualitative research is not new (Butler-Kisber, 2018), it is relatively novel in the area of asthma, sport and exercise (with the exception of Owton, 2012; 2013; 2018), and for those who identify as UK-resident South Asians, have asthma and participate in sport and/or exercise. Thus, the poems in this chapter aimed to provide a new and unique perspective in relation to the field of asthma, sport and exercise and South Asian culture. Miller (2018) provided an overview about why some disciplines including psychology, have remained resistant to creative approaches such as poetic inquiry. According to Miller (2018, p. 6), scholars continue to question the "…*legitimacy*" of creative approaches within the lens of positivist thinking, and choose to use the arguably safer framework provided by the traditional *"…linear, evidence-based tradition of writing and presenting research results"* (Boydell et al., 2014, p.4). Savin-Baden and Wimpenny (2014) argued, it is the fluidity and openness of arts-based research that makes it engaging, yet also challenging for academics. Faulkner (2007) argued that poetic approaches are considered challenging because it is difficult to determine what 'good' poetry involves.

In her article, aptly titled, 'Concern with craft', Faulkner (2007) argued that a critical issue for

those using poetic representations is the evaluation of such an approach. The question of, 'what is 'good' poetry?' is echoed by Faulkner (2007), as well as others (e.g., Percer, 2002; Furman, 2006). According to Faulkner (2007), poetic inquiry is not only about words or phrases, it is about focusing on the craft of poetry. Faulkner (2007) claimed that such attention will complement the success of 'good' research poetry and support the relationship between science and art. Attention to craft requires an attention to several aspects of the poem including *"…attention to images, to line, metaphor and simile, music, voice, emotion, story, and grammar"* (Faulkner, 2007, p. 8). Faulkner (2007) provided a criterion which can help researchers critique or judge the success of such poetic work. The criterion developed by Faulkner (2007) is detailed in the Table 14 (p. 157).

POETIC CRITERIA

Artistic concentration: The idea of 'feeling', rather than about, is what Hirshfield (1997) considered to be artistic concentration; the attention to language that connects, language that is *"…penetrating, unified, and focused, yet also permeable and open"* (Hirshfield, p. 3). It involves considerations of the history and presence of craft in poetry (see Percer, 2002) and manifests itself in careful attention to detail (titles, lines, punctuation, sound, rhyme, figurative language, and word choice) and feeling (tone, mood) (Faulkner, 2007).

Embodied experience: recognises the need for audiences to feel with, rather than about a poem, to experience emotions and feelings in situ. A poem should consider using images to transform the way that individuals look at the world (Faulkner, 2007; Hirshfield, 2007).

Discovery and/or surprise: the poem should teach the reader to see something familiar in new ways or ways that might be surprising. People can learn something new about the human condition and themselves (Faulkner, 2007; Owton, 2017).

Conditional: the partiality of the story should also be recognised through poetry, point of view as conditional while presenting what researchers may call 'narrative truth' (Faulkner, 2007).

Narrative truth: the facts presented should ring true, regardless of whether events, feelings, emotions, and images 'actually' happened (Faulkner, 2007; Owton, 2017).

Transformation: is about providing new insight, giving perspective or advocating for social change. It should ask the questions: *"Why am I being told these things? What will I know by the end of the poem I did not know before? Toward what end?"* (Hirshfield, 1997, p. 13).

Table 14. Poetic criterion, adapted from Faulkner (2007, p. 14).

According to Faulkner (2007), having a poetic criterion such as this, combines artistic and scientific insights to evaluate research poetry. In the current research, this criterion is discussed in reference to the poems presented in Chapter Six (see sections 6.2-6.9). Commensurate with Faulkner's (2007) argument, Carr (2003) suggested that poetic representations are valuable because they authenticate a person's lived experiences "…*while challenging researchers to learn about their abilities to communicate qualitative inquiry in a different way"* (p. 1330). Leavy (2015) argued that poetic representations of social scientific data can provide qualitative researchers with an alternative approach in which to appreciate and articulate lived experience. In this way, poetic representations offer an alternative way of representing research data, such as those from in-depth interviews (Leavy, 2015).

Richardson (1995), a prominent figure in poetic inquiry, has contributed to the theorisation of poetic representations and used the term "…*pleated texts*" (p. 1) to conceptualise the multiplicity of meaning that may emerge between what is there and what might not be there. The gaps that are left can enable interpretation for the reader. Richardson (1995) explained that this type of writing inspires the researcher to capture the rhythm, tonality and patterns that encompass speech, which enables researchers to extend their understanding of 'giving voice' to their participants. This is a significant aspect of many qualitative research paradigms, including phenomenologically-inspired approaches such as interpretative phenomenological analysis (Smith, Jarman & Osborn, 1999; Leavy, 2015), as well as contributing towards their understanding of representing data in different formats.

Poetic inquiry is one of the ways in which we, as qualitative researchers can learn about how to present our data differently and how to portray the key aspects of our data in a format which emphasises artistic concerns, as well as scientific concerns (Richardson, 1995). This in turn helps us to look at and interpret our data in different ways (Richardson, 1995). In the present study, I used poetic inquiry as a pathway to learn about how I could represent the participants' lived experiences in different formats. By communicating the findings in a different way, I aimed to amplify the participants' voices and represent their experiences in ways which could help the audience to interpret the data and make their own conclusions, whilst transferring this understanding to their own lives (Poindexter, 2000).

I chose to focus specifically on the embodied experiences of asthma and sport and/or exercise in the poems. This was influenced by my position as an 'insider', or a South Asian person who has asthma. As previously discussed (see section 4.7), I understand that my position influenced

the way I interpret my data. During this process of developing poetic representations, I selected what I felt was important to convey to the readers, based on my understanding of and my experiences of the corporeal, embodied experience of asthma. In the current research, this is important because having asthma is an embodied experience; one which involved participants to concentrate on how their body works and how their breathing is attended to, particularly during sport and/or exercise (see chapter Five for a detailed discussion). I focused on the corporeal experiences of the fear of death and complete physical restriction of the body, the sensuous nature and embodied act of breathing; a vital component of our being yet overlooked for those who do not experience respiratory problems. The participants' also mentioned that people often underestimated the impact of asthma and the embodied nature of having such a condition (see section 4.7.4), thus, the poems were developed to reveal the embodied and visceral nature of asthma and sport and/or exercise in a way which captured the audience's attention and enabled them to appreciate the corporeal implications of having asthma.

The way in which researchers represent their participants' words is important and there has been debate about how to do this effectively (Glesne, 1997). In poetic inquiry and to be able to present participants' words in a summarised piece of text, it requires researchers to deeply engage with, and reflect upon their findings over time (Breuer, Mruck & Roth, 2002). The act of poetry can therefore be considered as a method of 'inquiry' (Leavy, 2015), which could be employed to represent UK- resident South Asian adults' experiences of asthma, sport and/or exercise. Some researchers (e.g., Denzin, 1995; Richardson, 2002; Sparkes et al., 2003; Prendergast, Leggo & Sameshima, 2009) believed that expressive approaches such as poetic inquiry, are rigorous and insightful to qualitative research. As mentioned previously, alternative ways of presenting lived experiences (e.g., creative writing, poetic representations, and auto-ethnography) are now being utilised in the research field of asthma and sport research (see Owton, 2015; 2018), though such research remains scarce. The chapter now moves onto an overview of the research method of poetry.

4.12.2 Poetry as method

The 'research found' poem can be utilised as a means to represent the experiences of study participants in qualitative research (Furman, Lietz & Langer, 2006). This involves taking the words directly from the data, which is normally from interview transcripts (Patrick, 2016). Monica Prendergast (2009) offered a useful framework to characterise the different types of poetic representations of data, based on the voice involved in the poetry. Prendergast (2009)

suggested two categories of research found poetry: researcher-voiced and participant-voiced. The first category, researcher-voiced poetry, is somewhat problematic according to Prendergast (2009), since all poetic representations can be defined as 'researcher-voiced', but nonetheless can be the source of self-understanding, which can give rise to difficult emotions (Owton, 2017). The data for these poems originates from sources produced by the researcher, for example, auto-ethnographic data, such as: field notes; journal entries; or reflective and/or autobiographical entries (Prendergast et al., 2009, p. 23).

The second category relates to participant-voiced poetry. These poems are either developed by the researcher using the participants' interview transcripts, written by the participants themselves based on the data from their interview excerpts, or by the participants creating their own original poems (Prendergast et al., 2009). Although it is uncommon for participants to have access to their interview data to write poems from them, it can be completed particularly in participatory action research model studies, where the poems are co-authored with the researcher (Owton & Sparkes, 2017). This specific form of poetry should be used to honour the participants' language and the ways in which they speak, for example, their speaking styles, repetitiveness and pauses (Prendergast, 2009). For the purposes of the current research, I used participant-voiced found poetry, where eight poems were crafted from seven research interviews. This is because I discovered that my research necessitated an evocative portrayal of my participants' experiences, which illustrated the embodied interplay of asthma, sport and/or exercise, in order to make sense of and express chaotic, sensory experiences and powerful emotions. I acknowledge that, whilst participant-voiced poetry is about using the participants' words, ownership over the placement and ordering of these words lies with me, the researcher. Langer and Furman (2004) elaborated further and argued that when a researcher uses their participant's exact words in a condensed format in order to express the key message, this is called 'research poetry'. Given that I utilised participants' responses and their exact words from their interview transcripts, the approach in the current research was akin to 'research found poetry', where the aim was to evocatively portray moments in time, and the participants' experiences about asthma and sport and/or exercise in a compressed form.

I believed that poetry offered a practical way of representing what I found from my participants' experiences and I wanted to be able to use this imagery to 'step in' to the participants' world (Sissay, 2006); one that can be, at times, consumed by asthma. For example, the experience of an asthma attack is described in words by the participant but paints the picture of a person choking, gasping for air, fighting with their body in order to survive, which

could be a powerful image used to help enhance understanding. Poems emphasise the power of language and use metaphors, form and rhythm (Leavy, 2015). The process of constructing poems relies on sorting through the data to find words and phrases that can be used to illustrate meaning (Glesne, 1997; Prendergast, 2009). Thus, participant-voiced poetry focuses on the essence of a narrative, yet allows for multiple representations (Butler-Kisber, 2018). It is therefore arguably more evocative than the traditional linear texts, due to the embodied and melodic nature of the poem (Butler-Kisber, 2018).

As an example, Richardson (1995) used poetry to represent sociological interviews. In this way, Richardson (1995) used the words of the participant(s) to create a poetic representation of a phenomenon. Glesne (1997), motivated by Richardson's (1995) transformation of interview transcripts into poetry (poetic transcription), developed a process that could be used to create poetry from transcript data. Glesne (1997) called this process "…*poetic rendering*" (p. 206). Poetic rendering entails taking the participants' words, putting them into stanzas, and then deliberately removing words so that participants' intent and voice remain, but the text is more refined and evocative (Vincent, 2018).

Richardson (1995) and Poindexter (2002) created, what they termed, 'poem-like' pieces using their participants' data, to create an emotionally evocative section of words, aimed at creating a picture for the reader that an everyday conversation cannot (Spiers & Smith, 2016; Butler-Kisber, 2018). The process of creating participant-voiced poetry is not a linear one (Butler-Kisber, 2018). Leavy (2015) explained that it first requires distilling the narrative from the transcript and involves playing with the number of words, word sequences, pauses, breath points, and emphasis to reach the essence of the narrative, creating a rhythm and sound which reflects the voice of the participant. Therefore, the process of creating participant-voiced poetry is one which moves from linear thinking to a more embodied portrayal of the text, which represents feelings and essences in poetic form (Butler-Kisber, 2018). Furman (2004) proposed that by using imagistic language from the transcript, the reader is able to develop his/her own relationship with the text; what is known as resonance. The images then transform into knowledge for the reader and the visual or sensory images evoked by the poetic text allows the reader to explore the relevance of the text to their own life (Furman, 2012). The next section provides a discussion about how a poem can be constructed using interview data, and how poetic inquiry was applied to the experiences of UK-resident South Asian adults with asthma, and their sporting and/or exercising experiences.

4.12.3 Constructing poems

Owing to a disparity of academic literature in regard to the process of poetic inquiry, Owton (2017) specified how poetic representations can be developed. This was drawn on in the current research. Similarly, to other qualitative analysis techniques, such as IPA (Smith, Jarman & Osborn, 1999), Owton (2017) suggested that the researcher should read and re-read the interview transcripts in order to gain familiarity with the data. Once familiarity has been achieved, the transcripts can be searched for statements which may be distinct, or which strike the researcher's eye (Poindexter, 2002). Poetry can include *"…compression, image and metaphor", "…the clarification and magnification of being, through words",* or *"…the distillation of the essence of being, through language"* (Richardson, 2002, p. 146). In the current research, participants often used metaphors to describe how they were feeling in an attempt to evoke an image for the reader, for example, being "…*closed up into a web"* [Samina, Interview 1]. Additionally, Owton (2017) proposed that other devices, such as the use of repetition can be utilised in the construction of a poem (see Richardson, 2002; Öhlen, 2003; Gergen & Jones, 2008). Leavy (2015) suggested looking for themes of recurring language, then picking out exact words and phrases out of the data. These words then become the basis for the poem (Leavy, 2015). In this way, poetry offers researchers an additional way to provide participants with a 'voice' (Leavy, 2015), as with other forms of data including interviews (Smith et al., 2009). The researcher tries to interpret the participants' data and represent it in a way that preserves the speaker's voice (Leavy, 2015).

In the current research, I went back to the interview transcripts and notes. I worked digitally, cutting and pasting words and phrases that were distinct. It was a process of discovering which parts of the interview struck me emotionally. Glesne (1997) argued that care must be taken not to move the words too far beyond their original places in the transcript. If this happens, Öhlen (2003, p. 559) explained that this can "…*become a description too far from the narrated experiences of the participant*". Hence, I was careful not to distort the narrative told by the participant by aligning myself with Glesne's (1997) and Öhlen (2003)'s approaches. Following Glesne's (1997) style, I used the participants' words and used what Butler-Kisber (2018, p. 87) termed, "…*poetic license*", where sentences were formed by changing the order of the words. Owton (2017) explained that researchers should be aware of their role in the poetic construction process. I understood that each poem was shaped by me making interpretations based on the words that I chose, and that I was determining how each poem was developed.

I was specifically interested in the affective dimensions of asthma and recognised that participants' often used words that were associated with the senses, including hearing, taste and touch to describe their experiences. The latter aligns with a phenomenologically-inspired approach (Owton, 2017). This was mainly relevant when the participants were asked to describe their experiences of asthma attacks or when they had difficulty breathing. For example, in the current research, some participants described how their breathing was "*noisy*" [Aisha, Interview 1]. In this way, they wanted to illustrate to the reader what they meant, rather than tell them. Hogue (2006) explained that if the image is effective, this can help the reader to understand the world through senses, and enables he/she to consider the time, place and experience, and the emotions being conveyed in the poem. Sensory and aesthetic experiences of asthma are important, as it helps us to understand more about how asthma is experienced and understood (see Owton, 2013; Owton & Allen-Collinson, 2014), particularly for people who experience difficulties with breathing (Allen-Collinson, 2008; Owton, 2017), wheeziness or chest tightness. Therefore, poetry might help us to understand more about the bodily-felt sensory experiences of asthma (Owton, 2017) and to explore the meanings people with asthma attach to sport and exercise when they experience such bodily disruptive symptoms. Thus, the poems in the current research (see section 6.2-6.9) aimed to capture how UK-resident South Asian people experience asthma, sport and/or exercise and intended to 'show' rather than 'tell' the experience from the individual's perspective (Hanauer, 2015).

Below, an empirical example of how I developed a poetic representation from a participant's interview transcript is provided (see Table 15, pp. 164-166). In her research, Poindexter (2002) searched for phrases that were explicit, or unambiguous, and for expressions and wording which appealed to her. Commensurate with Poindexter (2002), I also searched for statements which were appealing to me and for sections of the transcripts which emphasised the participants' emotions. In essence, the aim of the poem was to provide an insightful perspective into *"…individual, subjective, literary and linguistically negotiated, emotionally laden descriptions of experience*" (Hanauer, 2010, p. 94).

Interview transcript	Poem – I can't breathe, I'm gonna die
Tasneem: from like sixteen to I'd say about eighteen (.) my asthma was quite bad like literally running up the stairs would umm **start off anxiety attacks** and stuff like that so I was diagnosed with anxiety as well (.) due to asthma (.) um I couldn't like **I had to drop out of football** I was **part of a football team** for like **five years** but I had to **drop out of it** because I **couldn't control my asthma** coz it WAS **NEW to me** like I couldn't control it I used to always get like **panic attacks** and stuff and end up in hospital um (.) like I **passed out** a couple of times as well [mm] like my whole **body went blue** [really] yeah and they were like oh she's stopped breathing and stuff and then I came back I dun it **happened twice** like that umm (.) so yeah my mum was like no **I don't want you to exercise anymore** I'm quite worried coz you're **always ending up in hospital** afterwards and stuff like that so I've had like **proper asthma** for now for like been diagnosed for like four five years (.) so I'm twenty three now Tasneem: It always starts off with (.) **it's always the asthma** like it starts off with an asthma attack like I can't breathe and stuff (.) and then the anxiety will kick in and I'll start **hyperventilating** like **my face will go** like (.) **blue or red** or something and **the doctors will be like she's hyperventilating you need to calm down you need to calm down but I can't calm down** coz I'm like oh my God I'm having an asthma attack again **I can't breathe I'm gonna die that's what I think every single time** I'm having one Tasneem: I literally **the only thing that's going through my head is breathe** that is it like when you fe when you feel like you're **choking on your own breath** like **it's a horrible feeling**	used to participate in a lot activities that involved exercise diagnosed properly, fifteen, sixteen became quite severe sixteen to about eighteen my asthma was quite bad running up the stairs start off anxiety attacks diagnosed with anxiety part of a football team, five years had to drop out of football couldn't control it, panic attacks end up in hospital, I passed out body went blue, stopped breathing mum was like no, don't exercise anymore felt really bad, can't even exercise part of a dance group, breakdancing, street dancing

	had to drop out of dance really passionate about dance, dance is al I live for, love dancing I can remember, dance rehearsals Really bad asthma attacks Every single time, start hyperventilating Every single time Face would go bright red I can't breathe it's always the asthma the doctors will be like she's hyperventilating 'you need to calm down, you need to calm down' but I can't calm down I can't breathe, I'm gonna die that's what I think every single time

when you are when you're in that time you you can't even breathe like (.) **it's just so horrible** like you **feel like you're gonna die** and then you **hear all these stories** about oh **this person died** with an asthma attack and so SOME WOMAN ON MY ROAD DIED WITH a asthma attack like last year (.) so **stuff like that GETS to me** like a bit I'm like oh my God **what if that happens to me one day** like I'm **not gonna be able to control myself** (.) when it comes to **breathing** like (.) you don't know really like if you can control it if you can't it's like (.) **if you can't control it you're dead** (.) so that's I obviously that's what starts the panicking off when I have an asthma attack but **it's just a horrible feeling** when you can't even breathe or you know **it's your body** and you can't even control it [yeah] Tasneem: Like back then obviously like I felt really bad that I can't even exercise (.) like I can't do what I wanna do like I loved football I used to like participate in everything also I was **part of a dance group** (.) like I do **breakdancing** and stuff like **street dancing** (.) so that's um based in Tamworth (.) and I **had to drop out of dance** as well and like I'm **really passionate about dance** like **dance is all I live for I love dancing** so I had to drop out of that for a while…	breathe, the only thing that's going through my head choking on your own breath it's a horrible feeling, it's just so horrible feel like you're gonna die hear all these stories, this person died stuff like that GETS to me what if that happens to me one day not gonna be able to control myself, breathing, it's your body if you can't control it, you're dead

Table 15. Example of creating a research poem - transcript extract and poem.

4.13 Conclusion

In this chapter, the research methodology and methods used in this research have been identified. This included a discussion about the different paradigms, interview techniques, analytical procedure (in this case IPA), reflexivity, ethical considerations and issues of validity in qualitative research.

The thesis now moves onto the central aspect of the study – the lived experiences of UK-resident South Asian adults with asthma who participate in exercise and/or sport. The next chapter (see chapter Five) presents the key themes developed using IPA.

Chapter Five: Findings and Discussion

5.1 Introduction

The previous three chapters provided an exploration of the literature about asthma, sport and exercise in the South Asian population; a discussion of the conceptual debates, in which the current research is grounded and the philosophical and methodological frameworks used to bring the experiences of asthma, sport and exercise in the UK-resident adult South Asian population to the fore.

This chapter describes the main findings from the 21 semi-structured interviews with 14 participants who have been diagnosed with asthma and were currently engaging in, or previously taken part in exercise or sport. Email responses from three participants conducted as part of follow-up inquiries have also been included. In line with the theoretical principles of IPA (see section 4.10), the analysis presented in this chapter involves interpretative accounts based on what the participants' have said. It is presented with reference to substantive and theoretical literature, to support the reported experiences (Smith et al., 2009). The analysis is informed by a symbolic interactionist (SI) perspective, including Goffman's (1959) performance theory of self (as discussed in section 3.3) and conceptualisation of stigma (see section 3.4). This chapter also draws on phenomenologically- inspired approaches, including Leder's (1990) 'absent body' and bodily dys-appearance (see section 3.5.1), and Zeiler's (2010) conceptualisation of the 'eu-appearance' of the body (described in section 3.5.2).

This chapter explores seven key superordinate themes; Negotiating the 'asthmatic' identity; Managing medication; Seeking non-pharmacological treatments; "Other South Asian's are lazy": Challenging cultural standards; Managing sport and exercise; Experiencing cultural stigma; Relationships with healthcare professionals. Each of the superordinate themes is presented with their subordinate themes. Table 16[14] (pp. 170-171) demonstrates which participants were represented within each superordinate theme.

Each of the themes was developed from exploration of the discussions with participants. Themes developed from different aspects of culture, sport and/or exercise and asthma, such

[14] Not all participants were included in each superordinate theme. The participants who were included are shown in Table 16.

as, the perceived severity of their asthma, medication taking behaviour, the use of non-pharmacological treatments and relationships with their HCPs from the participants' perspective.

Superordinate theme	Subordinate theme	Participants included
Negotiating the 'asthmatic' identity		Faheema, Dhaya, Lubna, Maryam, Tasneem, Samina, Priti, Nafisa, Jamal, Kalan
Managing medication		Samina, Tasneem, Maryam, Nafisa, Reena, Lubna, Faheema, Enayah, Jamal
Seeking non-pharmacological treatments		Nafisa, Reena, Maryam, Aisha, Samina, Jamal, Priti
"Other South Asians are lazy": Challenging cultural standards		Kalan, Aisha, Dhaya, Nafisa, Lubna, Faheema
Managing sport and exercise	1. Finding the right balance 2. Feeling self-conscious	1. Maryam, Enayah, Indiana, Reena, Jamal, Priti, Samina, Lubna, Kalan 2. Reena, Nafisa, Enayah, Maryam, Jamal, Priti

Experiencing cultural stigma	1. Dealing with misperceptions about asthma 2. Sport and/or exercise and the South Asian woman: Negotiating gender and cultural identities	1. Maryam, Nafisa, Kalan, Enayah 2. Dhaya, Nafisa, Lubna
Relationships with HCPs	1. Engaging in a therapeutic relationship 2. Unmet expectations of care	1. Nafisa, Kalan, Lubna, Priti, Tasneem, Indiana, Jamal 2. Samina, Dhaya, Faheema, Reena

Table 16. Participant theme table.

5.2 Negotiating the 'asthmatic' identity

One of the superordinate themes that developed from the participants' accounts was related to the way they negotiated their identity as 'asthmatics' and used different mechanisms to negotiate their asthmatic identity. Faheema and Dhaya debated about whether they considered themselves 'asthmatics', whereas Samina, Priti and Nafisa re-negotiated their asthmatic identity with themselves after a sudden reoccurrence of symptoms. For Samina, Priti and Nafisa, being symptomatic influenced them to reflect on and reconcile with the asthmatic identity. Dhaya and Lubna compared themselves against other asthmatics, who were perceived to be 'worse off'. Other participants, including Tasneem and Maryam perceived their asthma to be 'under control' and claimed that their asthma was rarely disruptive of their everyday lives. In complete contrast, Jamal and Kalan readily accepted the asthmatic identity.

This superordinate theme represented Goffman's (1963) insights on a social interaction strategy known as 'passing'. According to Goffman (1963), 'passing' involves *"…the management of undisclosed discrediting information about self"* (p. 42). Goffman's (1963) conceptualisation of 'passing' is based on the notion that an individual has a personally stigmatising feature about self and requires information about this stigmatising feature to remain undisclosed in social interactions (see section 3.4). It is the kind of information that marks someone as different, and in others' minds, changes them from someone who is normal, to someone who is "…*tainted, or discounted*" (Goffman, 1963, p. 42). According to Goffman (1963), people who can potentially be stigmatised by others are involved in 'passing':

> "…*because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent*" (p. 74).

Together with Leder's (1990) and Zeiler's (2010) phenomenologically-inspired concepts, including the 'absent' body, the 'dys-appearing' body (Leder, 1990) and the 'eu-static' body (Zeiler, 2010), this superordinate theme attempted to understand how some of the participants negotiate and 'perform' (Goffman, 1959) their identities as 'asthmatics'. Faheema and Dhaya questioned what is meant by having asthma and being an 'asthmatic'. When discussing whether they would self-identify with asthma, Faheema and Dhaya stated:

> *"…I don't think I have the proper asthma like everyone has. When someone says: 'do you have asthma?', I wouldn't really class myself as having asthma, but I still feel like I <u>need</u>*

the Ventolin [reliever inhaler], so I need it as an option where I have it if I get the symptoms" [Faheema, Interview 1]

"I think I wouldn't [diagnose myself with asthma]. I think a lot of people do get out of breath and no one's there that can run and not get tired. I think after that, if you do [get tired], it's a tiny bit more than somebody else [without asthma]. It's not that you probably couldn't recover without that [reliever] inhaler, I think I could manage without it but it's just easier cos you've got it [reliever inhaler], you might as well take it" [Dhaya, Interview 1]

Although they both self-identified as having asthma prior to the interview, Faheema's and Dhaya's accounts illustrated how they perceived themselves. Faheema, for example, explained that she does not have "*proper asthma*" and would not characterise herself as "*having asthma*". Similarly, Dhaya specified that she would not diagnose herself with asthma. Applying Goffman's (1963) analysis would indicate that Faheema and Dhaya were trying to 'pass' (Goffman, 1963) as someone without "*proper asthma*", or as someone without asthma. According to Goffman (1959), people actively negotiate roles in society. The asthmatic role can be associated with sickness, or illness, or what Leder (1990) termed as a 'dys-appearing' and/or 'dys-functional' body. Leder (1990) used the Greek prefix 'dys' (which signifies "*bad*", "*hard*", or "*ill*") to develop the term 'dys-appearance' (p. 84). Thus, the 'dys-appearance' of the body happens when the body appears to the individual as "*ill*" or "*bad*" (Leder, 1990, p. 84) (see section 3.5.1). If an individual does not agree with the expectations of this role, he/she might try to intentionally detach themselves from the role or not engage fully in the role performance (Goffman, 1959). This is known as role distancing and it involves de-emphasising the importance of the role (Goffman, 1959). According to Goffman (1961), extreme forms of distancing can involve total denial of a particular role. Faheema and Dhaya demonstrated some of this denial when they consistently self-identified as not asthmatic, or not having "*proper asthma*". It is also possible that they did not engage in role distancing (Goffman, 1959) because they were never in the role of asthmatic to start with.

The two accounts also showed another similarity. Both Faheema and Dhaya referred to others and compared themselves against other asthmatics. In doing so, they considered how others with and/ or without asthma presented themselves to others in social interaction. As quoted above, Dhaya believed that "*a lot of people*" without asthma "*get out of breath*" and argued

that there is not a single person who can "*run and not get tired*". Dhaya normalised the breathlessness that individuals can experience during sport and/or exercise. By doing so, she equated herself with people who experience breathlessness but do not have asthma. It is possible that she viewed herself as non- asthmatic because of this. Dhaya suggested that every person who runs can experience a 'dys- functional body' (Leder, 1990) when they get tired. For people with asthma, this tiredness and 'dys- functional' body (Leder, 1990) was only experienced a "*tiny bit more*" than others. Therefore, Dhaya believed that people with asthma are only affected a "*tiny bit more*" than people without asthma. This seemed to influence the way that she self-identified, that is, as someone who did not require treatment. Although both Faheema and Dhaya claimed that they did not have asthma or "*proper asthma*", they admitted that they used their reliever inhaler to treat their symptoms. The use of the reliever inhaler demonstrated a paradox in Faheema's and Dhaya's accounts, given that they continued to experience symptoms of asthma, albeit not "*proper asthma*", as quoted by Faheema.

According to Adams et al.'s (1997) typology (see section 3.3), the respondents who perceived that they did not have asthma were known as deniers, and those who admitted they have 'slight' or 'not proper' asthma were known as distancers. Since Faheema believed that she did not have *"proper asthma",* she would be labelled a distancer when applying Adams et al.'s (1997) insights. Dhaya, on the other hand would be recognised as a denier, when applying Adams et al.'s (1997) typology. Those who were characterised as 'deniers and/or distancers' in Adams et al.'s (1997) investigation rejected or distanced themselves from the social identity of an 'asthmatic', since their symptoms did not always persist. Adams et al. (1997) reported that those who denied their asthmatic identity dissociated themselves from role of the asthmatic. Goffman (1961) argued that this type of behaviour could constitute *"…a wedge between the individual and his role, between doing and being and can result in identity confusion or a diminished identity*" (p. 108) (see section 3.3). In the current research, Faheema suggested that her condition was not "*chronic*":

> *"…with me, because I'm normally okay, I don't really think I have anything like more of CHRONIC kind of condition… I've had it for a time, but I wouldn't say it's chronic because I don't have it all the time, it's just random episodes during the year when I need it [reliever inhaler]"* [Faheema, Interview 1]

In this account, Faheema believed that her condition was something that affected her "*during random episodes*". The reduced use of her reliever inhaler and the perception that she was "*normally okay*" influenced her belief that her condition was not chronic. In their research, Adams et al. (1997) found that deniers and distancers perceived their condition as acute, instead of a long- term chronic illness. Faheema's account supported this, however, it was unclear whether Faheema distanced herself from the asthmatic identity at all times because she used the reliever inhaler when she was acutely unwell. This suggested that this 'distancing' of the asthmatic identity was context- dependent, that is, Faheema distanced herself from the asthmatic identity when she perceived herself as being 'well'. This links to Leder's (1990) concept of the 'absent' body (see section 3.5.1). Faheema's conversation indicated that by experiencing an 'absent' body (Leder, 1990) (see section 3.5.1), that is, having an asthma-body which was "*normally okay*" (as quoted above), it enabled her to distance herself from the identity of a "*chronic*" asthmatic. Dhaya questioned whether her condition ever affected her in a "*really bad way*":

> *"I didn't actually know whether it [asthma] affected me in a REALLY BAD WAY. I'll always have my inhaler, I had to go for the <u>yearly</u> check-up with the GPs, but other than that, I've never actually felt out of breath because I've been asthmatic, it's been normal for me, even in P.E [physical education class], I think I was pretty much okay…"* [Dhaya, Interview 1]

Although Dhaya believed that her asthma had not affected her in a "*really bad way*", she admitted to carrying her inhaler and visiting her GPs for her yearly asthma review. In doing so, it could be argued that she performed what might be considered part of the 'normal' expected social order (Goffman, 1963) for someone with asthma. This included having her inhaler on her person and going for yearly check-ups. However, because she has not "*actually felt out of breath*" due to her asthma, Dhaya considered herself to be "*normal*", rather than "*asthmatic*". As previously mentioned, she explicitly stated that she did not experience breathlessness because she was asthmatic. This supported Leder's (1990) concept of the 'absent' body. Dhaya's belief that she was asymptomatic led her to normalise her identity and to disassociate herself from the identity of 'asthmatic'. Dhaya's account provided a clearer representation of someone 'denying' the asthmatic identity, as advocated by Adams et al. (1997), when she characterised herself as 'normal'. However, this did not necessarily mean that Dhaya

completely disassociated herself with the asthmatic identity because she followed the 'normal' expected social order when she visited her GP and used her reliever inhaler. These were part of her role expectations as a person with asthma. Similarly, to Faheema, Dhaya's denial of the asthmatic identity was dependent on whether she experienced symptoms and whether this affected her presentation of sporting self. Further, Goffman (1963) argued that people engage in the act of "*passing for normal*" (p. 87). These data demonstrated that Faheema and Dhaya were trying to 'pass for normal' or as people without "*proper asthma*". The absence of symptoms and the absence of a 'dys-functional' body (Leder, 1990) in front of others enabled Faheema and Dhaya to act as people without asthma. For Dhaya, the absence of symptoms during sport and/or exercise allowed her to 'pass for normal' during her physical education (P.E) classes:

> *"I've not really had much of a bad experience… I'VE SEEN OTHER PEOPLE and they've had asthma and they've had difficult times in P.E, but it's just not been me"* [Dhaya, Interview1]

Dhaya reiterated that she was markedly different to other people with asthma. She spoke in a louder tone to emphasise this. According to Dhaya, this was because other people with asthma had visible difficulties during P.E, while she did not display her asthma-body in this way. It is possible that she did not experience symptoms in this particular situation. The absence of symptoms enabled her to keep her asthma-body-self concealed from others and allowed her to 'pass' (Goffman, 1963) as someone without asthma. In the account above, Dhaya discussed her sporting self, when breathlessness was normal for many without asthma. In Dhaya's view, people with asthma who were unable to conceal their asthma-body-self during exercise was what she believed to be characteristic of having an 'asthmatic' identity. This fits with Goffman's (1963) insights on 'passing' and 'role distancing'. When Dhaya's asthma-body-self was revealed to others and she could no longer 'pass for normal', she minimised the impact of her condition by comparing herself against other people. This was an act of role distancing (Goffman, 1963) whereby she de-emphasised the role of asthma in her sporting lifestyle. When Dhaya was asymptomatic, there seemed to be denial of the role of asthmatic altogether.

Comparing against other asthmatics who were perceived to be 'worse off' was a common strategy used by other participants. If the presentation of the asthma self in the front regions (Goffman, 1959) of one's life was associated with recurrent symptoms or a 'dys-appearing'

body (Leder, 1990), this allowed the asymptomatic person with asthma to minimise their own condition. For example, Lubna described the perceived impact of her asthma:

> *"I wouldn't describe it as bad because I know people have it all year round, people have symptoms every day. I don't have symptoms every day, so I wouldn't say it's bad asthma, it's still asthma but it could be a lot worse"* [Lubna, Interview 1]

In this account, Lubna compared herself against people with asthma who have symptoms *"all year round"* (as quoted above) and de-emphasised the impact of her asthma in an everyday context. Unlike Faheema and Dhaya, Lubna recognised that it was "*still*" asthma and accepted the asthmatic identity as part of her personal identity. According to Adams et al.'s (1997) typology, those who accepted the asthmatic identity were known as accepters. In this sense, Lubna would be classed as an accepter, yet, she engaged in behaviours similar to the distancers and deniers by stating that she did not have 'bad asthma'. By comparing herself to 'other' asthmatics, Lubna shared a similarity with Dhaya when she tried to distance herself from other people with asthma, who were believed to have symptoms all year round. Lubna, like Faheema and Dhaya, engaged in role distancing and distanced herself from the 'sick role' (cf. Parsons, 1975) associated with the asthmatic identity. In Ferguson's (2015) research on homeless people, she found that her respondents attempted to disassociate themselves from their roles because being homeless was often associated with a low status and other negatively evaluated roles. Thus, Ferguson (2016) argued that when individuals find themselves cast into roles in which their social identities suggested are inconsistent with their actual or desired self-conception, they engage in role distancing. In the current research, it was evident that Lubna engaged in role distancing in order to differentiate herself from the 'sick' role (cf. Parsons, 1975), which might have been a negatively evaluated role, commensurate with Ferguson's (2016) proposition. According to Adams et al. (1997, p. 198), those who accepted the asthmatic identity, but believed their asthma was not of the "*acute*" type were known as pragmatists. It is possible that Lubna would be characterised as a pragmatist, rather than an accepter, distancer or denier, since she accepted her asthmatic identity but insisted that she did not have 'bad' asthma. This adds new insight to Adams et al.'s (1997) typology by demonstrating that pragmatists and deniers and distancers engage in role distancing and compare themselves against 'other' asthmatics.

Like Lubna, Maryam and Tasneem accepted the asthmatic identity as part of their personal identity. Maryam, however, compared herself to others who did not control their asthma well. She described her asthma as being "*under control*" throughout her interview: *"I never had an asthma attack I don't think. I don't know why, I always had my asthma in control, it wasn't really bad"* [Maryam, Interview 1]. She differentiated between why having asthma can be considered a "*good thing*" or a "*bad thing*":

> *"I think asthma can be a good thing and a bad thing, so, good thing I would say, I don't experience an asthma attack… for me, it's not that bad, cos I manage it and it's under control, it depends if you manage it"* [Maryam, Interview 1]

For Maryam, having asthma was a "*good thing*", as long as she did not experience an asthma attack. In essence, as long as her asthma was perceived to be under control and her asthma-body remained in the corporeal background or was 'absent' (Leder, 1990), this constituted good control. This also enabled Maryam to engage in role distancing (Goffman, 1963) when she minimised her asthma status. In contrast, having asthma would be defined as a "*bad thing*" if it involved experiencing asthma attacks. According to Maryam, when someone experienced an asthma attack, it denoted a lack of control and possibly, an ineffective attempt at self-managing asthma. Tasneem shared a similar view:

> *"…it used to affect it [exercise and/or sport] really badly before when I was younger, cos I've been dancing since I was thirteen but I can remember in school, dance rehearsals, I used to get really bad asthma attacks, and every single time, I'd start hyperventilating, literally every single time, I'd get an asthma attack, so, hyperventilating, breathing quite deeply and my face would go bright red"* [Tasneem, Interview 1]

Tasneem described her past experiences of her asthma to illustrate how her condition affected her sporting performances. Similarly, to Maryam, Tasneem suggested that the experience of having recurrent asthma attacks during her dance rehearsals constituted "*really bad asthma*". This links with Leder's (1990) notion of the 'dys-appearing' body (see section 3.5.1). In Tasneem's case, the experience of *"hyperventilating"*, *"breathing quite deeply"* and her face going *"bright red"* depicted a loss of control of the asthma-body and the 'dys-appearance' of the body (Leder, 1990). When Tasneem began to experience the discomfort of hyperventilation and breathlessness, she moved to a reflective state of bodily awareness where she was drawn to the hurt body part (see section 3.5.1). This is when the body appeared to Tasneem as "*bad*" or "*ill*"

(Leder, 1990, p. 84). In Tasneem's case, prior to the experience of *"hyperventilating"* and *"breathing quite deeply"*, her focus was directed towards her dance rehearsal, and she was pre-reflectively aware of her body. When she attended to the hurt body part, this intentionality was disrupted. In essence, the experience of an asthma attack disrupted her mind-body-world relation (Zeiler, 2010). In the following account, Tasneem explained that her asthma is *"not as bad as it used to be"*:

> *"…now, I can control my asthma. It's not as bad as it used to be, it's probably cos I was younger then, literally now, I can dance, I can play football and I can control it"* [Tasneem, Interview 1]

This account by Tasneem demonstrated her ability to play football and be involved in different sports because she was now in "*control*" of her asthma. In Leder's (1990) terms, when Tasneem was focused on her sporting activity (in this case, dancing and football), she was experiencing an 'absent', or 'dis-appearing body. In this account, she remained pre-reflectively aware of her asthma-body during her sporting performance, and this allowed her to perceive her asthma as being under control. Tasneem continued to reiterate this throughout her interview:

> *"I don't feel like my asthma's bad at all, it doesn't kick in as much as it used to, my asthma's fine, [spoken non-chalantly] it's so calm, I know how to control it"* [Tasneem, Interview 1].

Similarly, to Tasneem, Samina recalled her past experiences with asthma in order to understand her asthmatic identity:

> *"…before, it was it was completely mild, to be honest, for me, it was non-existent, then as the years went by, I noticed from the age of 16, it became more exercise-induced, so every time I'd do exercise, I'd need my inhalers and I'd really struggle…"* [Samina, Interview 1]

Samina described her asthma identity and her asthma-body as being "*non-existent*" and *"completely mild"* when she was younger. She then discovered that her asthma-body was affecting her sporting progress. The recurrence of asthma from the age of 16 led to Samina re-negotiating her asthmatic identity. When asthma was dormant, Samina's asthma-body remained in a 'dis-appearing' (Leder, 1990) bodily state of awareness. In the past, her asthma-body was, in Samina's words, *"non- existent"*, or 'absent' (Leder, 1990) from conscious

awareness. When her symptoms re-appeared, she moved away from an 'absent' body to a 'dys-functional' bodily mode of being (Leder, 1990). Using Goffman's (1959) self-presentational analysis, Samina was able to self-present as someone without asthma because her asthma was *"non-existent*". She was 'passing' (Goffman, 1963) as someone without asthma, and the absence of symptoms enabled her to keep her asthma-body-self concealed from others. When she realised that her asthma was exercise-induced, Samina found it difficult to keep her asthma-body-self hidden. When this occurred, Samina's identity as someone with *"non-existent"* asthma changed. According to Samina, having an asthmatic identity can at times, be a "*very insignificant*" part of one's self:

> *"…to me, unless it's at a moderate to severe stage, it can be a very insignificant thing, but once you're at that stage where you've had an asthma attack and you know it's getting worse, it can be very debilitating"* [Samina, Interview 1]

In her view, Samina suggested that the asthmatic identity was particularly "*insignificant*" when the asthma-body remained 'absent', or in the corporeal background (Leder, 1990). When the body appeared 'dys-functional' (Leder, 1990) and became "*debilitating*", the asthma identity held different meaning. Priti shared a comparable experience to Samina, and described having to re- negotiate her asthmatic identity when her symptoms became more prevalent after engaging in exercise:

> *"It [asthma] came when I was young and then it got better, and then when I started exercising, it [asthma] got worse again, so I thought it was gone, I thought the asthma was gone but no, so I needed to take the inhaler properly"* [Priti, Interview 1]

Priti discovered that her asthma was often triggered during exercise. Previous to this, Priti believed that her asthma had "*gone*". Instead, when her symptoms re-appeared, she stepped back into her role as an asthmatic. Like Samina, Priti was 'passing' as someone without asthma when she thought that her asthma was "*gone*". Priti and Samina used their inhalers to treat their physiological symptoms, which in turn, enabled them to conceal the asthma-body-self once their symptoms were under control. When Samina and Priti's asthma-body-self interrupted their sporting progress and their sporting sense of self, this influenced them to reconcile with their asthmatic identity. In short, when Samina and Priti experienced symptoms during exercise and/or sport, they could not 'pass as normal' (Goffman, 1959), or as someone without asthma. According to Goffman (1963), individuals who are attempting to 'pass as

normal' often experience increased levels of anxiety "*…in living a life that can be collapsed at any moment"* (p. 87). It seemed, that when symptoms appeared, Samina and Priti could no longer 'pass as normal' (Goffman, 1963) and reverted back to using their inhalers to control the presentation of their asthma self to others. Similarly, Nafisa questioned her identity as an "*asthmatic*" after a sudden recurrence of symptoms after several years:

> *"…14 years I considered myself to be no asthma… because I literally didn't need my inhaler… and then radically during the flu, for the past couple of years before I met you, but other than that, yes, I'd say I didn't think I was an asthmatic but now, I would say I was an asthmatic"* [Nafisa, Interview 1]

Nafisa's account demonstrated that her identity as an "*asthmatic*" was linked to her physiological health. She considered herself to be an "*asthmatic*" only after her symptoms re-appeared and whether she needed to use her inhaler to treat her symptoms. Using Goffman's (1963) analysis would suggest that it was easier to 'pass as normal' when Nafisa was asymptomatic for several years. Passing is deemed successful when someone is considered 'normal' (Goffman, 1963). In this case, it was when the participants kept their asthma-body-self concealed by taking their inhalers when symptoms emerged. This account also showed that Nafisa either denied or distanced herself from the asthmatic identity when she considered herself to have *"no asthma"* (as quoted above). In Adams et al.'s (1997) typology, Nafisa would have been classed as a denier or distancer. She quoted that she "*didn't think*" she was an asthmatic because, similar to Samina and Priti, her asthma-body was 'absent' (Leder, 1990). For approximately 14 years, Nafisa was not reflectively aware of her asthma-body because there was an absence of symptoms. When her body appeared as 'dys- functional' or 'ill' (Leder, 1990) and called for action (Zeiler, 2010), that is, when symptoms re- appeared, Nafisa's identity changed from someone with "*no asthma*" to an "*asthmatic*".

When she began taking her inhalers, Nafisa shifted from being a denier and/or distancer to an accepter. As mentioned previously, being acutely unwell can influence whether someone accepted the asthmatic identity or distanced themselves from it. Adams et al. (1997) did not account for this in their typology. However, the current research has indicated that the asthmatic identity is not static. The meaning of such an identity can depend on the physiological impact of the condition. The current research also adds new insight to Adams et al.'s (1997) research by incorporating Leder's (1990) concept of the 'absent' and 'dys-

appearing' body to understand how the appearance of the body can contribute to this shift between denial and acceptance. According to Samina, Priti and Nafisa, the 'asthmatic' identity was related to the appearance of symptoms and in Samina's and Nafisa's case, it was linked to the consistency of symptoms. Applying Leder's (1990) insights would indicate that being an 'asthmatic' meant experiencing a 'dys-functional' body (in this case, symptoms of asthma) and remaining in a 'dys-functional' bodily state, requiring the body to be treated (in this case, using inhalers).

Unlike other participants, Jamal acknowledged that his asthma was chronic: *"I'm pretty sure that my asthma's chro[nic], I'll <u>have</u> it for the rest of my life"* [Jamal, Interview 1]. For Kalan, accepting that his body was acting in a 'dys-functional' (Leder, 1990) way enabled him to accept his diagnosis:

> *"…when I was a teenager, I just accepted the fact that something had gone wrong with my body and therefore, I had to deal with it"* [Kalan, Interview 1]

Adams et al. (1997) would characterise Jamal and Kalan as 'accepters'. In Jamal's case, the acceptance of the chronic nature of asthma was akin to expecting that his asthma-body-self may afflict him for the rest of his life, thus embracing the longevity associated with the asthmatic identity. Kalan expressed attachment to his asthmatic identity almost immediately by recognising that "*something had gone wrong*", and that he needed to "*deal with it*". Kalan went on to say:

> *"[the diagnosis] didn't really bother me because give [me] an inhaler, that seems to solve the problem and then I could just get on with things"* [Kalan, Interview 1].

In contrast to deniers, distancers and pragmatists, accepters accepted the necessity of both preventer and reliever medication (Adams et al., 1997). The use of an inhaler was thus accepted as part of Kalan's asthmatic role and used to diminish the risk of disruption to the presentation of his asthma-self.

5.2.1 Summary

It was evident that some of the participants engaged in identity negotiation and aimed to 'pass for normal' (Goffman, 1963) using different strategies. For example, Nafisa, Samina and Priti re-negotiated their asthmatic identity with themselves after experiencing a sudden recurrence of symptoms. When Samina, Priti and Nafisa were asymptomatic, their asthmatic identity was not

considered to be an integral part of their self. It is possible that this was because they could 'pass as normal' when they were asymptomatic. It is at this time that they tried to negotiate a non-asthmatic identity. When they were symptomatic however, their 'dys-functional' body (Leder, 1990) influenced them to reconcile with the asthmatic identity. This could be because they were unable to 'pass for normal'.

One of the strategies used to negotiate their asthmatic identities involved comparing themselves against other asthmatics. Faheema, Dhaya and Lubna, for example, considered how others with and/ or without asthma presented themselves to others in social interaction. As long as their symptoms were not revealed to others and they could 'pass for normal', Faheema and Dhaya perceived themselves as people without asthma, or "*proper*" asthma. From Dhaya's perspective, people with asthma who were unable to conceal their asthma-body-self, particularly during sport and/or exercise, were characteristic of having an 'asthmatic' identity. Lubna and Dhaya engaged in role distancing by comparing themselves against other asthmatics who were believed to be 'worse off'. Maryam and Tasneem also engaged in role distancing, when they judged their ability to manage their condition effectively. As long as there was a perceived sense of control, Faheema, Dhaya, Lubna, Maryam and Tasneem were content about how their asthma self was presented to others.

Although Goffman (1963) argued that people engage in 'passing' behaviours to avoid being stigmatised, it was unclear in the current superordinate theme whether the participants attempted to 'pass as normal' and negotiated their identity as 'asthmatics' to avoid stigmatisation. In terms of 'passing' strategies (Goffman, 1963), this superordinate theme revealed that some of the participants attempted to 'mask' (Goffman, 1959) their asthma-body selves from others. Using the inhaler in times of symptomatic distress to conceal the asthma-body-self influenced some of the participants, including Priti, Samina and Nafisa to re-consider their asthmatic identity. For others, including Faheema and Dhaya, the use of the inhaler to treat symptoms was paradoxical. This is because Faheema and Dhaya could be engaging in an extreme form of role distancing (Goffman, 1959), where they detach themselves from the asthmatic role. It is also possible that Faheema and Dhaya did not engage in role distancing at all because they consistently self-identified as someone without asthma, or "*proper*" asthma. Applying Adams et al.'s (1997) typology, it was evident that many of the participants were either pragmatists or distancers.

In complete contrast to those who tried to 'pass' using the reliever inhaler, Jamal and Kalan seemed to accept the asthmatic identity and readily incorporate it into their lifestyle. These participants seemed to embrace the asthmatic role and identity. This included taking the inhaler regularly to minimise disruption to the performance of the asthma self. This leads to the following superordinate theme, which explores the participants' accounts with regard to their medication taking behaviour.

5.3 Managing medication

Some of the participants described the use of their inhalers and other medications, leading to the superordinate theme of 'managing medication'. The self-management of asthma requires having to remember to take regular medication (see section 1.7) (Pinnock, 2015). This is the case for people with asthma who have been prescribed a preventer inhaler and who have been told to follow a prescribed regime (Pinnock, 2015). Prevention has been recognised as an integral part of self- management, yet failure to adhere to prescribed regimens is common amongst people with asthma (Adams et al., 1997). In the current research, Leder's (1990) and Zeiler's (2010) phenomenologically-inspired insights and Goffman's (1959) self-presentational analysis were applied to understand the participants' experiences of adherence and non-adherence to prescribed medications.

Samina explained that it was difficult to remain compliant because she had "*never cared*" about her asthma:

> *"I never used to take it [preventer], I was non-compliant, and then with this [asthma attack], the pink one [preventer] they [HCPs] put me on and then all these different ones and it was quite sad, especially because I don't care about my asthma because it's never been a serious thing for me, I've never cared so I've never been compliant to it, EVEN NOW, I really struggle to be compliant, which is not good"* [Samina, Interview 1]

After experiencing an asthma attack, Samina was still unable to reconcile herself with an 'asthmatic' identity; one that involved taking regular medication. When her HCPs prescribed her with preventer medication, Samina was "*sad*" because this seemed to threaten her identity as someone without asthma. As previously discussed (see section 5.2; 'Negotiating the asthmatic identity'), Samina believed that her asthma was *"non-existent"* for several years. Using Goffman's (1959) concept of role distancing, it seemed that Samina isolated herself from her asthma role through indifference. According to Goffman (1963), when individuals engage in role distancing, they are not denying the role, rather, they are denying the virtual self's expectations implied in the role. For the asthmatic role, the virtual self's expectations related to taking inhalers as prescribed. Samina was, however, unable to commit to her 'asthmatic' role, when she did not comply with her medication regime. Instead, she further embedded herself in the identity of non-asthmatic by not taking medication.

As previously discussed, (see sections 1.2 and 2.2.4), UK-resident South Asians were more likely to be hospitalised due to poor management of asthma (Griffiths et al., 2001; Sheikh et al., 2016). One of the main reasons for this increased risk of hospitalisation has been linked to non-adherence (Griffiths et al., 2001; Sheikh et al., 2016). Where previous research (e.g., Griffiths et al., 2001) has suggested that South Asians were less likely to be adherent because they did not understand the purpose of their preventer medication, Samina's account indicated that she was non-adherent because asthma was never an integral part of her identity. For Tasneem, being prescribed a preventer inhaler served to highlight the severity of her asthma:

> *"I used to be on the blue one [reliever inhaler] but they've [HCPs] put me on the brown one [preventer inhaler] now… when I was on the blue one, I thought my asthma's not that bad, it's fine, when they put me on the brown one, I started going higher and higher with inhalers, I thought: 'oh my God, is my asthma that bad that now I have to take a brown inhaler?'"* [Tasneem, Interview 1]

When she was prescribed a preventer inhaler, Tasneem perceived that this meant that her asthma was becoming more severe. Tasneem explained that she *"started going higher and higher with inhalers*", which meant that she was being prescribed additional therapies to control her asthma. A person's treatment approach varies according to the severity of their condition (Morrison, 2016) (see section 1.7), with their treatment depending on the variation in their condition over time using the step-wise approach (BTS, 2016). For Tasneem, the use of additional therapies changed the way she felt about her asthma and meant that she needed to re-consider her asthma status. When she was "*going higher and higher and higher with inhalers",* this served to enforce the idea that she had "*bad*" asthma. This supports Leder's (1990) concept of the 'absent' body, since it is possible that being prescribed a preventer inhaler meant that her body appeared to her as 'dys-functional'. The use of the preventer inhaler then, might be related to notions of a 'dys-appearing' body (Leder, 1990). In essence, the representation of a preventer inhaler and other additional therapies served to reinforce the idea that the body is 'dys-functional' (Leder, 1990) and that it will remain that way, even when the asthma-body might appear to the person as 'well', or what Zeiler (2010) termed as 'eu-static'. When a person's body appears to him/her as positive, 'good', 'easy' or 'well', this is called being in a 'eu-static' mode of being (Zeiler, 2010, p. 1) (see section 3.5.2). Although Tasneem was frustrated that she was prescribed a preventer inhaler, she explained that she did not use it regularly:

> *"I literally don't even take my [preventer] inhaler anymore. Back when I was younger, it [asthma] was <u>really</u> bad, now I don't feel like I need an inhaler, but here and there, I feel <u>really</u> wheezy and I feel like 'oh my God, I need my inhaler'"* [Tasneem, Interview 1]

Tasneem explicitly stated that she did not use her preventer inhaler because she believed that she did not need one. Tasneem may have believed that she did not require a preventer inhaler because there was a perceived sense of control. The terminology used by Tasneem, for example, "*but here and there*" suggested that she was trying to present herself as someone who did not experience recurrent symptoms. Tasneem used her preventer inhaler when she felt "*really wheezy*", or when her body appeared to her as 'dys-functional' (Leder, 1990). The use of the preventer inhaler seemed to be influenced by the way Tasneem's body appeared to her as either 'dys-functional' or 'absent' (Leder, 1990). Additionally, it seemed that the reliever inhaler was used to hide symptoms of asthma from others, thus, it could be seen as an act of trying to mask the asthma-body-self in an attempt to pass as normal (Goffman, 1963). A 'mask' refers to withheld information about oneself (Goffman, 1963). According to Adams et al. (1997), Tasneem would be classed as a pragmatist. Adams et al. (1997) explained that pragmatists were similar to the deniers and distancers because they did not use their prophylactic medication (at least according to their prescribed regime), but unlike the deniers and distancers, pragmatists accepted that they had asthma. Maryam demonstrated a similar point of view to Tasneem. She explained that she only used her inhalers if she needed to feel a "*difference*":

> *"I'm okay, if I take them [inhalers], I don't feel anything, so I <u>see</u> the difference when I'm having troubles with my asthma and when I'm not, so when I'm having trouble then I <u>do</u> feel that something happened, something made me to breathe easier and I feel good, but when I'm okay then I don't feel anything, it's the same"* [Maryam, Interview 1]

As mentioned previously (see section 5.2; 'Negotiating the asthmatic identity'), Maryam negotiated her asthmatic identity based on her perception of control. Here, Maryam suggested that as long as there was a perceived sense of control over her condition, she felt "*okay*". Maryam explained that she used her inhalers, only when she was experiencing symptoms, or what she called, "*troubles with her asthma*". When her body remained in a 'dis-appearing' bodily state of awareness or more specifically, when her asthma-body was 'absent' (Leder,

1990), she did not feel that her inhalers made a "*difference*" to her asthma-body. On the other hand, when she experienced "*trouble*", she sought out her inhalers to treat her problematic or 'dys-functional' body (Leder, 1990). Zeiler (2010) argued that a bodily mode of being that is experienced as painful and distressing to the person calls for attention and action by the person. Thus, when Maryam experienced "*troubles*" her asthma, her body called for attention and for something to help her "*breathe easier*". After she used her inhalers for relief, she moved away from a 'dys-appearing' body, to one where she felt "*good*". According to Adams et al.'s (1997) typology, Maryam and Tasneem could be categorised as either pragmatists or distancers (see section 3.3). Adams et al. (1997) explained that, in their research, pragmatists and distancers shared similarities, as both groups claimed that they experienced symptoms intermittently and sought to distance themselves from using their preventer inhaler. However, Adams et al. (1997) also argued that distancers tried to avoid identifying as 'asthmatic', yet in the current research, Maryam and Tasneem accepted their asthmatic identity, with Maryam incorporating her condition into her personal identity when she referred to it as "*my asthma*". It is more likely that Maryam and Tasneem shared similarities with pragmatists, rather than distancers. Other participants also believed that they experienced symptoms intermittently and tried not to use their preventer inhaler, unless absolutely necessary. Nafisa questioned the necessity of the preventer inhaler:

> *"…I'm not sure I need [it] cos I manage quite well, sometimes medicine half the time makes you do things unnecessarily. I'm not sure I need them [preventer inhalers]"*
> [Nafisa, Interview 2]

According to Maryam's, Tasneem's and Nafisa's accounts, if the body was 'absent' (Leder, 1990) from conscious awareness, then the preventer inhaler was not used. In this account, Nafisa criticised the medical paradigm for prescribing medication which she believed was unnecessary. She explained that she managed her asthma well, therefore she did not require a preventer inhaler. It seemed that the use of a preventer inhaler implied that her condition was not under control, or that she was not managing her asthma well. In the account above, it seemed that Nafisa was not experiencing symptoms which allowed her to believe that she was managing her asthma "*quite well*". The use of a regular preventer served to conflict with this perception. Nafisa reiterated the view that the preventer inhaler was only required when she experienced a 'dys-functional' body (Leder, 1990): *"when I need it, I need it, and I have no complaints with the reliever, I'm not so keen on taking the preventer*" [Nafisa, Interview 1]. Nafisa clarified that she

did not enjoy using the preventer inhaler. The BTS (2016) guidelines state that the preventer inhaler should be used daily, whereas the reliever inhaler should only be used when necessary. Nafisa recalled a recent experience when she was given a preventer inhaler after experiencing symptoms:

> *"…got really bad in the summer again, just over a couple of weeks 2, 3, 4 weeks I think, where I had to take it [reliever inhaler] a lot and then I went for my asthma check and she [HCP] gave me a preventer this time. She [HCP] said that: 'maybe you need to start taking [preventer inhaler]', I was given a preventer… came home and literally the next day, I wasn't wheezy, so I didn't take the preventer and I was fine"* [Nafisa, Interview 2]

In this account, it was evident that Nafisa was experiencing symptoms during the summer. She used her reliever inhaler to treat these symptoms. At the time, Nafisa did not have a preventer inhaler, she had only been prescribed a reliever. After noticing that she was using her reliever inhaler "*a lot*", her HCP prescribed a preventer inhaler in line with treatment guidelines. This suggested that Nafisa's HCP followed the 'normal' social order by prescribing treatment as part of her 'treater' role. Nafisa, however, did not follow the expectations required of her as an asthma patient. It was suggested in the previous superordinate theme (see section 5.2; 'Negotiating the asthmatic identity') that Nafisa shifted from being a denier and/or distancer to an accepter. In this account, it seemed that Nafisa did not accept that she needed regular medication and was thus ascribing to pragmatist behaviour, rather than accepter behaviour.

According to Nafisa, this is because her asthma-body shifted from a 'dys-functional' (Leder, 1990) bodily state (in this case, when she was wheezy) to a 'dis-appearing' (Leder, 1990) bodily state of awareness (in this case, when she was not wheezy) without the use of the preventer inhaler. This, however, would be short lived because the underlying inflammation would not be treated. Preventer treatment is endorsed by the BTS (2016) guidelines to treat the underlying inflammation. Applying Goffman's (1959) insights would suggest that because underlying lung/bronchial inflammation is not a visible symptom, it can be ignored. For example, in Nafisa's case, as long as she was asymptomatic in her performance of asthma self, that is, when her symptoms were not visible, she could 'pass for normal' (Goffman, 1963). Thus, the preventer inhaler was not required because it was not used to hide the asthma-body-self. Instead, it was used to treat the underlying bronchial inflammation. The latter, however, was not visible to her or to others, therefore was less of a concern compared to visible symptoms.

Reena shared a similar view to Nafisa about reducing the use of the preventer inhaler during an absence of symptoms:

> *"I'm supposed to take it [preventer inhaler] in the morning each day, if I'm being completely honest, I don't. Now the season is hay fever season and I take it more regularly now, when it's not the season I tend not to, cos I think I can manage my asthma now a lot better, if they [HCPs] find out, I'll be in trouble probably… I don't really want it taking inhalers unnecessarily"* [Reena, Interview 1]

Reena, who has been prescribed a preventer inhaler, believed that her asthma was now a *"lot better".* Although she understood that she was supposed to take her medication every day, she explicitly stated that she did not. Reena implied that this information was unknown to her HCPs. This issue is discussed in further detail later on in this chapter (see section 5.8.2). According to Reena, her asthma-body remained in a 'dys-functional' bodily mode of being (Leder, 1990) during the hay fever season. It was because of this that she took her inhalers more regularly during this time. The absence of a 'dys-functional' body (Leder, 1990) influenced Reena's decision to reduce the use of the inhaler during symptom-free periods. Leder's (1990) insights indicate that the preventer inhaler should be used by the person with asthma during times of bodily 'dis-appearance', that is, when the asthma-body remains 'absent' to the person. Nafisa's and Reena's accounts, however, have suggested that the preventer inhaler was only used during times of bodily 'dys-appearance' (Leder, 1990). For Reena and Nafisa, adherence was about their perceived sense of control of their condition, with the aim to try and reduce medication. Like Nafisa, Reena believed that medication should only be used when it was necessary: *"I think you should use more medical stuff when it's absolutely necessary"* [Reena, Interview 2]. Reena explained that she would only use her inhaler if her body shifted to a 'dys-functional' state (Leder, 1990) and if she was forced to conceal her asthma-body-self:

> *"I will only take my inhaler now… if I'm actually physically wheezy or if I can feel cos I've got a lot of allergies as well, so, if I think I've had a small reaction and I need to just get it into check immediately, then I'll just take it"* [Reena, Interview 2]

Similarly, to Nafisa and Reena, Lubna chose when to use her preventer inhaler:

> *"I'm not taking my inhalers <u>now</u> because I don't have to, it's not that point of the year where I'm <u>having</u> to take my inhaler or I'm having to <u>worry</u> about my allergies,*

> *sometimes when I clean, when the dust comes out, my asthma does creep up again and I have to take my inhaler straight away but I take the Ventolin [reliever] inhaler, that relieves my symptoms immediately, so that's quite nice"* [Lubna, Interview 1]

Lubna explained that her symptoms only appeared at specific times of the year. This indicated that she was able to 'pass as normal' (Goffman, 1963) in the seasons where she was asymptomatic. Although she had been prescribed a preventer inhaler to use every day (see section 4.4.1), Lubna believed that "*it's not that point of the year*", where she needed to use her preventer inhaler or worry about her triggers. When her asthma "*does creep up*", her reliever inhaler was effective at targeting the symptoms. This enabled Lubna to shift away from a 'dys-functional' (Leder, 1990) bodily state to 'eu-statis' (Zeiler, 2010), when she felt "*quite nice*" almost immediately after taking her reliever inhaler. It seemed that for Nafisa, Reena and Lubna, the aim was to try and reduce the use of the preventer inhaler and this was based on symptom perception. This could be classed as pragmatist behaviour, according to Adams et al. (1997), who reported that pragmatists believed that they did not require preventer medication (see section 3.3). Reliance on the reliever inhaler during times of symptom distress can be clinically dangerous (NHS, online, 2018). A recent press release by Asthma UK (2019b) has shown that the death rates have increased by more than 20% in five years.

Faheema explained that, although she was prescribed a preventer inhaler when she was younger, she did not use it:

> *"I've never used it. I had never opened it, so I'd never used it, I just had it with me… I didn't have it on prescription anymore because I didn't need it"* [Faheema, Interview 1]

It was mentioned previously (see section 5.2; 'Negotiating the asthmatic identity'), that Faheema might not have been engaging in role distancing (Goffman, 1959) because she was never in the role of asthmatic to begin with. In the current superordinate theme, her account demonstrated that the use of a preventer inhaler would influence her to reconcile with and incorporate the asthmatic identity into her personal identity. This matches Adams et al.'s (1997) typology, who argued that deniers and distancers did not use preventer medication and relied on their reliever medication.

In complete contrast, Enayah and Jamal accepted the necessity of medication and adhered to their medication regime to control their condition; an approach recommended by HCPs: *"I just kinda stick to my prescribed inhalers and leave it to that"* [Enayah, Interview 1]. As mentioned previously (see section 5.2; 'Negotiating the asthmatic identity'), using the preventer inhaler regularly could be viewed as 'accepter' behaviour. Jamal elaborated on the role of preventer and reliever medication in his life:

> *"…one of the best ways that I incorporate my asthma into my lifestyle, making sure that I <u>have</u> it on me at <u>all</u> times which means if it gets out of control during the day or during the night, I always have something to <u>manage it</u> and taking those two puffs in the morning and two in the night with the purple [preventer] inhaler definitely <u>means</u> that I <u>don't</u> have to use that [reliever inhaler] most times…"* [Jamal, Interview 1]

Jamal insisted that his preventer medication was one of the key variables in his asthma self-management. By taking his preventer medication regularly, which he referred to as his purple inhaler, he did not need to rely on his reliever inhaler. He believed he was in control of his asthma because of his medication. From a clinical perspective, this illustrated good control and was a clear demonstration that the preventers were working to reduce inflammation and control attack risk (BTS, 2016). It is unclear whether Jamal experienced better long-term control as a result of this strategy. Jamal's use of preventer medication fits with Adams et al.'s (1997) insights, who proposed that accepters were more likely to use their preventer medication. Adams et al. (1997) reported that accepters were equally as concerned with deniers and distancers to lead a normal life. The difference was that accepters coped by taking their medication regularly, rather than avoiding it or denying that they needed medication (Adams et al., 1997) (see section 3.3).

Additionally, when applying Goffman's (1959) self-presentational analysis, Jamal's account indicated that he might be using the preventer inhaler to help conceal his asthma-body-self for a longer period of time. The preventer was beneficial physiologically, and also helpful for Jamal to 'pass as normal' for a longer duration when compared to using the reliever inhaler regularly. By using the preventer inhaler every day, his asthma-body-self remained hidden. The regular use of the preventer also meant that Jamal did not need to use his reliever inhaler to conceal his asthma-body-self if it *"gets out of control"*. This differed strongly with other participants' accounts (including Tasneem, Maryam, Nafisa, Faheema and Dhaya), who

seemed to rely on their reliever inhalers to treat symptoms and mask their asthma-body-self when symptoms began to disrupt their performance of asthma self. Jamal described how his preventative treatment helped him to conceal his asthma-body-self in an everyday context:

> *"The PURPLE [preventer] one, I'll feel fine and you don't notice a change, it's not like your lungs suddenly feel stronger. I'll TAKE the purple inhaler and I'll just go about my day but I will notice that you just don't need your blue one as much, so I'll notice that, wait, I've done this, I'm not wheezy, HAD I not been taking this regularly, I would actually be a lot, I would actually be wheezy and I would need to use my blue inhaler"* [Jamal, Interview 1]

Jamal explained that his purple preventer inhaler was used to physiologically treat the underlying lung/bronchial inflammation. This implied that Jamal understood that the preventer inhaler was not used for immediate relief. Moreover, Jamal recognised that without using preventative treatment, his symptoms would persist, and the reliever inhaler would have to be used more frequently.

Where it was suggested that other participants, such as Nafisa, did not use their preventer inhalers because it did not have any interactional benefit, it was evident that Jamal considered how preventative treatment aided his performance of asthma self. Furthermore, applying Leder's (1990) insights would indicate that Jamal was not only treating his symptoms when they emerged or when he experienced a 'dys-functional' body. Instead, he was using the preventer inhaler to remain in a 'well' bodily state, or in 'eu-statis' (Zeiler, 2010). This subsequently allowed Jamal's asthma-body to remain in control or 'absent' from his conscious awareness (Leder, 1990). This was in complete contrast to other participants, including Maryam, Tasneem, Nafisa, Reena and Lubna, who turned to their reliever inhaler when their body 'dys-appeared' or appeared to them as 'bad' or 'unwell' (Leder, 1990).

5.3.1 Summary

This superordinate theme developed from the evidence of the participants voicing their medication management strategies throughout the interviews. The participant's accounts revealed that there was an association between experiencing symptoms and using medication, suggesting that they are reactive to symptom perception. When Maryam, Tasneem, Faheema, Lubna, Nafisa and Reena, were asymptomatic, medication was stopped. When applying Leder's (1990) insights, this suggested that the inhaler was used when the participant experienced a

'dys-appearing' body, or when they experienced symptoms. When the participant was asymptomatic, or when the body appeared as 'absent' (Leder, 1990) to these participants, treatment was stopped. Using Zeiler's (2010) notion of the 'eu-static' body, this indicated that medication was stopped when the body felt 'good' or 'well' and when the body was in 'eu-statis'. When they experienced symptoms and moved to a 'dys- functional' bodily state of awareness (Leder, 1990), the asthma-body-self called for action, where Maryam, Tasneem, Faheema, Lubna, Nafisa and Reena, used their inhalers to conceal their asthma-body-self. During times of bodily 'dis-appearance' (Leder, 1990), however, the asthma-body did not call for treatment, therefore the preventer inhaler was not used. This is consistent with the evidence related to non-adherence in UK South Asian asthma populations (e.g., Griffiths et al., 2001; Hussein & Partridge, 2002). The accounts also revealed that non-adherence was not necessarily linked to the absence of symptoms. Samina, for example, did not adhere to her medication regime because she did not care about her asthma. Using Goffman's (1959) concept of 'role distancing', it seemed that Samina detached herself from her asthmatic role when she perceived it to be insignificant to her sense of self. Samina was, thus, unable to commit to her 'asthmatic' role and continued to distance herself from the role by being non-adherent.

In terms of Goffman's (1959) analysis, it is possible that the preventer inhaler was not deemed to have any interactional benefit and was thus, not used regularly. For example, Nafisa explained that when her asthma-body shifted from a 'dys-functional' (Leder, 1990) bodily state (when she was wheezy) to a 'dis-appearing' (Leder, 1990) bodily state of awareness (when she was not wheezy), she did not use the preventer inhaler. This was because she felt better when her wheeziness went away. Using Goffman's (1959) insights suggested that because the underlying lung/bronchial inflammation was not a visible symptom, it was easier to ignore. For example, in Nafisa's case, as long as she was asymptomatic in her performance of asthma self, that is, when her symptoms were not visible, she could 'pass for normal' (Goffman, 1959). This meant that the preventer inhaler had no interactional benefit for Nafisa, therefore, it was perceived to be unnecessary.

In complete contrast, Jamal insisted that his preventer medication was one of the key variables in his self-management of asthma, which fitted with Adams et al.'s (1997) insights. Applying Goffman's (1959) analysis indicated that Jamal regularly used his preventer inhaler, as part of his interactional management of asthma self, where he used his preventer inhaler to conceal his asthma-body-self for longer periods of time. Additionally, Jamal used his preventer inhaler to

treat his underlying lung/bronchial inflammation even though it was not visible. The following superordinate theme switches focus from the use of pharmacological treatment and explores the participants' perspectives about using non-pharmacological treatments to treat asthma.

5.4 Seeking non-pharmacological treatments

For people of South Asian origin, traditions and values are often associated with South Asian countries, such as, India, Pakistan, Sri Lanka, Bangladesh, Bhutan, Maldives and Nepal, where the practice of different religions, including Islam, Sikhism, Hinduism and Christianity practice is common (Fleras & Elliot, 2007) (see section 1.9 for an overview of South Asia). There are cultural differences between South Asian countries and Britain and UK-resident South Asians are exposed to cultural values of the East and West (Zaidi, Couture-Carron & Maticka-Tyndale, 2016, p. 232). Wardak (2018) argued that it becomes imperative for South Asian families to socialise their children to the cultural beliefs of the East, whilst living in a Western culture.

This was evident in the participant's discussions, where cultural influences played a part in managing health. From childhood, South Asians are socialised by other members of their community about cultural and religious traditions, including using alternative treatments, such as homeopathy, or herbal remedies (Mukherjee, 2001) (see section 2.2.4). Reena's, Maryam's, Nafisa's and Aisha's accounts demonstrated the use of homeopathy, Tibb medicine and other types of herbal remedies to help treat asthma symptoms, which led to the emergence of the superordinate theme of seeking non-pharmacological treatments. Maryam and Aisha also discussed their use of spiritual practices which were rooted in their Islamic faith. These types of non-pharmacological treatments were often connected to the participants' sociocultural background. In contrast, Samina, Indiana, Priti and Jamal tried not to use culturally-specific alternative treatments, believing them to be ineffective when compared to mainstream medical practice. Theoretical insights from Goffman (1959), Leder (1990) and Zeiler (2010) were applied to understand the participants' experiences of seeking non- pharmacological treatments.

Nafisa explored the homeopathic approach for a short period of time in her early 20s:

> *"I made my own independent decision at twenty-one to do the homeopathy where I did <u>just</u> the one, homeopathy, and I left the conventional"* [Nafisa, Interview 1]

> *"He [homeopathic practitioner] said: 'don't have dairy for six months and don't use your inhalers'. It treated my asthma, I didn't use my inhaler till pretty much my daughter was*

born in 2010, so eight years that I didn't use an inhaler at all, probably like one off once a year" [Nafisa, Interview 1]

Nafisa's accounts demonstrated that she moved away from the "*conventional*" medical paradigm, which states that the preventer inhaler should be used regularly (BTS, 2016). She believed that the homeopathic approach "*treated*" her asthma. In response to the efficacy of this approach, she did not use her inhalers for eight years until pregnancy began to trigger symptoms. For Nafisa, the homeopathic approach enabled her to remain well. Her body remained in 'eu-statis' (Zeiler, 2010) for several years, where an inhaler was not used. This fits with Goffman's (1963) analysis on role expectations and role performance. Nafisa's conversations indicate that the role expectations of being an asthma patient contradicted with being a homeopathic user role. Nafisa's accounts suggest that she fulfilled her role expectations of being a homeopathic user when her homeopathic practitioner told her to stay away from her inhalers. This, however, led to her breaching the role expectations of her asthma patient role, where she was expected to follow the Western convention of using her inhalers regularly. The two roles were incompatible and conflicted with each other.

Thus, Nafisa experienced role conflict because of the opposing role obligations of her Western-influenced medical asthmatic role and her South Asian-influenced homeopathic user role. Before she sought out homeopathy, Nafisa explained that she used her inhalers regularly:

"I was always using preventers and inhalers and through secondary school, I was just using a preventer inhaler every day because that's what I was told to <u>do,</u> and I wasn't allowed to question it, so that's what I did" [Nafisa, Interview 1]

This account illustrated that Nafisa was not allowed to question her role expectations as an asthma patient, which required her to be adherent. It was part of the 'normal' expected social order in the Western-influenced medical paradigm for Nafisa to use her medication regularly. Nafisa explained that she wanted to distance herself from the medical paradigm and her role as an asthma patient. This was because she believed it enabled her to understand whether or not she needed inhalers to treat her asthma:

"…since my homeopathy and coming off the inhalers for a short while I do feel that, had I not done that, I'd have been on the same prescriptions all my life, which were unnecessary" [Nafisa, Interview 1]

Using homeopathy allowed Nafisa to have autonomy of her decisions with regard to her treatment approach. Nafisa indicated that the medical paradigm was restrictive, in the sense that her treatment approach would not have changed. As mentioned previously (see section 5.3; 'Managing medication'), Nafisa questioned whether she required preventer medication and was characterised as a pragmatist. Here, it is possible that her use of alternative treatments is linked to her pragmatist behaviour because she used these treatments to reduce the use of Western medication. This adds new insight to Adams et al.'s (1997) typology, who only investigated a White Caucasian asthmatic population and did not explore how cultural identity can influence treatment behaviour. The decision to breach the role expectations of her Western-influenced medical asthmatic role and explore the homeopathic approach seemed to have been influenced by her belief that she was receiving "*unnecessary*" medication. According to Goffman (1959), role conflict can occur when the individual disagrees with the responsibilities of what a particular role should be (Goffman, 1959). In this case, Nafisa disagreed with her role as an asthma patient within the Western-influenced "*conventional*" medical paradigm. Nafisa explained that, from a clinical perspective, having an 'asthmatic' identity was linked to notions of taking the preventer and reliever inhaler throughout one's lifetime:

> *"…so, had I not taken that step myself, I wouldn't have found that out. I would still be taking my reliever and preventer my whole life because that would be what they were forcing me to do because I am an asthmatic"* [Nafisa, Interview 1]

Nafisa believed that her decision to seek out homeopathy helped her to distance herself from using her inhalers regularly and detach herself from the 'normal' expected social order associated with her role as an 'asthma patient'. She suggested that this strengthened her autonomy and her freedom to make choices about her treatment approach, whereas if she had not sought out homeopathy, she would have been prescribed with further medication. This fits with Leder's (1990) phenomenologically-inspired insights. Nafisa's account demonstrated that from the Western healthcare perspective, taking preventer and reliever medication was associated with having a 'dys-functional' body, even when the body appeared to the asthma patient as 'eu-static' (Zeiler, 2010). According to Nafisa, regular treatment was part of her role expectations as an asthma patient, irrespective of whether she felt her body was in 'eu-statis' (Zeiler, 2010). In complete contrast, the homeopathic user role did not obligate her to use her inhalers at all:

> *"…he said to me: 'just stop using them if you don't need them' and it because HE SAID THAT I DID AND I DIDN'T use them [Nafisa laughs], and I didn't, had he not said that, I would have continued to this day using preventers and I actually didn't need them"* [Nafisa, Interview 1]

When the homeopathic practitioner told her to stop using her inhalers, Nafisa interpreted this as the homeopathic practitioner giving her permission to stop using pharmacological treatment. This seemed to influence her decision to distance herself from the Western-influenced asthma patient role. This was distinctively different to the *"…aggressive military metaphorical conceptualisations of the body"* (Lupton, 2012, p. 131) in Western-influenced medical care, which is about treating symptoms instead of looking at the person's overall wellbeing (Birch, 2019). Nafisa continued to practice the homeopathic approach as a health management strategy. She described using a holistic medicinal philosophy known as Tibb medicine (see section 2.2.4), which she explicitly stated was informed by her 'South Asian' values: "*I've been raised doing that in culture, but also because of what I've learnt through the Tibb medicine, I do believe it to be true"* [Nafisa, Interview 2]. She discussed the significance of Tibb medicine in an everyday context:

> *"…Tibb medicine, prophetic medicine, and I still do go by that. It was always mentioned as I was growing up, and its certain foods that you eat, so a hot temperament which I am, my body's hot, so I will react to hot foods if I have a lot of mango or dates, I will come out in spots*" [Nafisa, Interview 2]

Nafisa explained that her choice to use Tibb medicine was influenced by her childhood. The Unani-Tibb treatment system was heavily influenced by Hippocrates (460-366 BC) (Mukherjee, 2001) (see section 2.2.4), who introduced the 'humoral theory' of disease and described the wet and dry characteristics of the different humours that constitute the human body. One of the main principles of Tibb medicine is that the body has the ability to heal itself and thus, therapies used in accordance with the Tibb philosophy should support this belief (Jabin, 2011). It is possible that the use of inhalers was not perceived as an appropriate therapy for the Tibb philosophy. Choosing to abide by this approach seemed to contribute to an expression of Nafisa's 'South Asian' self. Nafisa described how a person's temperament was based on his/her personality and it was characterised by their response to illness: *"it's [temperament] how you react to the illnesses, but also, personality"* [Nafisa, Interview 2]. She also clarified that

temperament is associated with the homeopathic approach: *"…temperament… its homeopathy"* [Nafisa, Interview 2]. She described her own personality as: "*definitely fiery*", [Nafisa, Interview 2], which she matched with her temperament of "*hot and phlegmy*" [Nafisa, Interview 1]. This information was then used to adapt her lifestyle behaviours by, for example, avoiding certain foods such as "*mango or dates*" (as quoted above). According to Keval (2009), South Asian communities believed that traditional remedies were effective and efficacious towards treating illness and providing balance in the body.

Hall, Griffiths and McKenna (2015), used an SI approach to explore alternative treatment usage in pregnant women, and found that there was a conflict between alternative treatments and the conventional medical paradigm. In their research, many of the women felt frustrated when they had to deal with incongruent expectations, such as, wanting to use herbal remedies and not being permitted to by their HCPs (Hall et al., 2015). In the current research, Reena explained that she would only use her inhaler if she experienced wheeziness:

> *"I will only take my inhaler now, which is really, I'd get in trouble for it from the Western point of view, is if I'm actually physically wheezy…"* [Reena, Interview 1]

Here, Reena believed that she would get into 'trouble' if her HCPs discovered that she was not taking her inhalers regularly. This was because there is a role expectation to use inhalers regularly for asthmatics, as previously demonstrated by Nafisa's accounts. Using non-pharmacological treatments contradicted with this role expectation. Reena discussed how alternative treatments, such as turmeric, were introduced to her in childhood:

> *"I didn't really get a formal diagnosis until I was probably in my late teens; college; university, cos I <u>had</u> asthma but my mum wouldn't let me take a pump, cos she didn't want me to have a pump, so she used to use very traditional methods like brown sugar and turmeric"* [Reena, Interview 1]

Although Reena knew that she was experiencing symptoms of asthma, her mother did not want her to use an inhaler, or a "*pump*". Similarly, to Nafisa, Reena was socialised to believe in the efficacy of non-pharmacological approaches, including turmeric and brown sugar. She elaborated on this:

> *"…she [Reena's mother] just didn't think I needed it in those days. I think, me and my brother [who had also been diagnosed with asthma], both of us, we didn't get any*

asthma pumps until much later. She used to just give us herbal stuff, don't think they really understood it either, but I think on top of that, they thought they could deal with it, so they dealt with it" [Reena, Interview 2]

Reena explained that her mother used "*traditional*" ways of treating asthma. This was because medical intervention was perceived to be "*unnecessary*". Reena's mother believed that she could "*deal*" with asthma without the use of an inhaler, partly because her mother did not understand much about the condition. This signifies the importance of both sides being educated about contrasting treatment approaches. HCPs require education about cultural beliefs and its impact on treatment use. In the same way, South Asian groups require education about the value of Western medical intervention. However, learning about cultural health beliefs is complex because of the heterogeneity of ethnic backgrounds (Wen Jin, Slomka & Blixen, 2002). According to Wen Jin et al. (2002), it is near impossible for HCPs to learn about every different ethnic group. One approach suggested by Wen Jin et al. (2002) towards understanding more about cultural beliefs is to simply ask the patient about his/her perceptions about treatment. This can help the HCP to avoid making assumptions about their patient's heritage and recognise that their patient might have different beliefs about treating illness. In the current research, it was evident that Reena's mother's treatment approach differed with the pharmacological approach, which asserts that prophylactic medication is the most effective method to treating asthma (BTS, 2016). It was evident that Reena's mother's approach to treating asthma contrasted with the role expectations of the Western-influenced asthma patient role.

In Singh et al.'s (2002) study (see section 2.2.4), which investigated attitudes towards non-medical treatments for asthma, it was reported that at the time of an asthma attack, many of their respondents sought to alleviate symptoms by using treatments they had made at home. According to Singh et al. (2002), hot substances such as tea, were used to provide relief by almost half of their sample. Other ingredients including ginger, turmeric, cloves, sugar crystals and light meals, were also believed to be provide relief, although, an explanation as to how these substances provided relief was not provided by Singh et al. (2002). In the current research, Reena described how turmeric and brown sugar were used to help treat her symptoms:

"You put the brown sugar, you put the turmeric in it, mix it up and just swallow, basically, you got to swallow it, no water, nothing like that. The brown sugar is

soothing, and the turmeric is anti-inflammatory" [Reena, Interview 1]

Reena's account indicated that the turmeric was perceived to have anti-inflammatory properties, which worked to reduce inflammation. Previous evidence has reported that turmeric actively inhibits inflammatory pathways in the body (Bone & Mills, 2012) (see section 2.2.4), though, there has been no evidence to suggest that turmeric is effective for treating asthma symptoms. In the current research, Reena believed that the combination of turmeric and brown sugar worked well: "*…it did*

used to work believe it or not, it used to take the edge off the asthma really well" [Reena, Interview 1]. In terms of Leder's (1990) and Zeiler's (2010) insights, Reena perceived that she shifted from 'dys- function' to 'eu-statis'. However, this was not always the case:

> "*…it wasn't a very good experience when I was young, cos I used to sit there holding onto the sofa, not being able to breathe, and your mum's trying to give you turmeric and brown sugar"* [Reena, Interview 1]
>
> *"…I just had to learn to fight through it, the symptoms, you try and calm your body down and just think about what you're doing and not allow yourself to get overwhelmed by it because you don't have a choice"* [Reena, Interview 1]

It seemed that the combination of turmeric and brown sugar was used to help Reena "*fight*" her symptoms without medical intervention. Although this was not easy for her, Reena believed that traditional treatments, including the use of turmeric and brown sugar helped her learn how to "*calm her body down*" and to not "*get overwhelmed*" by her symptoms (see section 6.6 for a poetic representation of Reena's experiences). Reena's account demonstrated how she 'fought' with her 'dys-appearing' body to achieve 'eu-statis' (Leder, 1990; Zeiler, 2010). It was evident that from an early age, Reena learned how to conceal, or mask the asthma-body-self without the use of an inhaler. It also showed that this was a traditionally-valued way of treating asthma. Reena remarked that using turmeric was a treatment which had been passed down to her: *"…it's to do with generations of things, remedies that have been passed down really*" [Reena, Interview 2]. She reiterated throughout that she used traditional remedies because that was how she was raised: *"…that's the way I've been brought up"* [Reena, Interview 2]. These early experiences influenced Reena's response towards medical intervention and her decision to use alternative treatments in adulthood:

> *"…at the time, I didn't have that experience of an inhaler…, even now, I think if I'm not feeling too bright, I will just have hot warm water with turmeric in it every morning or I'll put honey in it, so I don't really use my inhaler very much"* [Reena, Interview 2]

Reena seemed to prefer to not use her inhaler and so, took hot water with turmeric to help treat her 'dys-function' (Leder, 1990). It is possible that this was due to being socialised to believe that turmeric was effective at treating her symptoms. Prasad and Aggarwal (2014) (see section 2.2.4) reported that turmeric was often used as a traditional non-pharmacological treatment in Ayurvedic practice. For example, in Pakistan, it was used as an anti-inflammatory treatment, whereas in India, it was used to purify the blood (Prasad & Aggarwal, 2014). Reena suggested that if her traditional methods did not work, she would resort to using her inhaler to mask her asthma-body-self:

> *"…if my traditional methods, my haldi [turmeric] in the morning and a bit of warm water and stuff wasn't working, I'll take the inhalers. I would take whatever's necessary…"* [Reena, Interview 2]

This resonated with the previous superordinate theme (see section 5.3; 'Managing medication'), where Reena stated that she would only use their inhalers when her body appeared to her as 'dys- functional' (Leder, 1990). This account also illustrated that that the use of her inhalers was context- dependent. In short, Reena would adopt her Western-influenced asthma patient role when her body called for action and was 'dys-appearing' (Leder, 1990). In line with the Western-influenced medical paradigm, Reena would use her inhalers to achieve 'eu-statis' or a 'dis-appearing' bodily state (Leder, 1990; Zeiler, 2010). This was heavily dependent on what she perceived as "*necessary*". Reena believed that the inhaler acted as a 'quick fix' and that there was a risk of dependency:

> *"I think you should use more medical stuff when it's absolutely necessary… when you know there's no other route, otherwise your body I believe, develops a resilience to it, develops a habit and then you're gonna need it so to speak"* [Reena, Interview 2]

> *…it's your body then… it's using the turmeric which is anti-inflammatory it's using things like the honey…* [Reena, Interview 1]

Turmeric and honey, on the other hand, used the body's ability to shift from 'dys-function' to 'eu- statis' (Leder, 1990; Zeiler, 2010). It is possible that this fitted with what Reena believed to

be, traditionally-valued ways of responding to asthma; one which did not rely on the inhaler as a 'quick fix'. This type of approach held symbolic meaning for Reena. When she was prescribed a preventer inhaler, Reena felt conflicted:

> *"…subconsciously I then felt like I've managed all these years, do I <u>really</u> want to take Western medicine in order to <u>control</u> it?. I'd say for a good few years in between, I didn't take to it. I kind of tried to manage it by avoiding the triggers, as opposed to allowing the triggers to, so, if it was dust in the way, I just avoided it. I stayed away from as many of those environments I could"* [Reena, Interview 1]

In this account, Reena explained that she was unsure about whether to adopt a Western-influenced asthma patient role; one which required her to use her inhalers. This contrasted with the way she had been brought up, which was to 'fight' through the symptoms and would have involved a re-negotiation of roles. In order to distance herself from adopting the asthma patient role, Reena sought out another approach. This involved avoiding her triggers. This tactic helped Reena to 'pass as normal' (Goffman, 1963) and was less of a threat to her 'South Asian' sense of self than using medical intervention. According to Reena, avoidance of triggers was a 'South Asian' tradition in itself, as demonstrated in the following extract:

> *"…my grandmother used to get asthma and her chest used to flare and she had pistachio nuts, so, what they do is peel it, so she would have boiled them. In those countries you know your triggers and you just avoid them…"* [Reena, Interview 1]

Reena drew on her grandmother's experiences with asthma, who used pistachio nuts to treat her symptoms. Reena's grandmother lived in India, and Reena noted that in India, and possibly other less developed countries, learning about and avoiding triggers was an integral way to mask the asthma-body-self, and present as 'normal' (Goffman, 1963). It seemed that for Reena, using alternative treatments and avoiding triggers were a way for her to keep in touch with her traditions. Reena added that other South Asians were losing sight of their traditions as Asians:

> *"… [South Asian] people <u>need</u> to change their attitudes because what they're doing is, they're taking on too much of a Western way of doing things, which <u>obviously</u> as <u>Asian's,</u> we've managed to avoid a lot of this stuff because of our traditions"* [Reena, Interview 1]

> *I THINK OUR [South Asian] CULTURE has <u>lost</u> that and that's why so many of our children are now having asthma, inhalers and all the rest of the stuff because they don't*

> *realise this is centuries and centuries of stuff that's been put in place for a reason, so we need to try and maybe turn back the clock, stop relying [on medical treatment]. I mean, it might sound prejudiced, but it's not prejudiced, I'm not being prejudiced, we're made differently, we're British born and bred. I am so proud of being British, but our bodies are still made differently…"* [Reena, Interview 1]

Reena claimed that UK-resident South Asian people were more likely to adopt a Western-influenced patient role, which she believed increased the chances of developing asthma. In the above two accounts, Reena illustrated how there was cultural conflict between a Western-influenced society and her heritage as a South Asian. She argued that British South Asians have been exposed to the Western way of treating illness. The latter part of Reena's account suggested that there were different ways to achieve an 'absent' body (Leder, 1990), or 'eu-statis' (Zeiler, 2010), for British South Asians. This involved "*turning back the clock*" and 'relying' less on medical intervention, or
"*Western*" ways. According to Reena, the traditions have been "*put in place for a reason*", that is, for South Asians to embrace their South Asian self.

Both Nafisa's and Reena's accounts suggested that they were at times resistant towards using their inhalers. In doing so, Nafisa and Reena seemed to embrace their 'South Asian' self by seeking out alternative treatments. These treatment approaches were informed by Reena and Nafisa's sociocultural context; one which espoused naturally-sourced ingredients as treatment and one which seemed to reduce the use of Western medication. This also enabled them to distance themselves from a Western-influenced medical asthmatic role and its expectations to use their inhalers regularly. Additionally, it was evident that these treatments were used when Nafisa's and Reena's asthma-body was 'absent' from conscious awareness (Leder, 1990), or when they believed they were in 'eu-statis' (Zeiler, 2010). When they were ill or when they experienced a 'dys- functional' body (Leder, 1990), Nafisa and Reena turned to their inhalers for relief.

Singh et al. (2002) explained that symptoms relating to asthma, such as, the common cold or a cough were treated using hot remedies which include cinnamon powder and honey mixed in warm water or boiling leaves of basil, black peppercorns, crushed cloves and crushed ginger in piping hot water by their respondents. In the current research, Maryam's and Aisha's accounts revealed that they used ginger, turmeric, and honey as a health management strategy:

> *"I have ginger tea, which is really good, and with mint, it really helps with cough. I take all the time ginger tea now. I'm used to it, so every day I take, I think it feels good. My mum says: 'you should make sure that your chest is warm', so that's why I drink everyday ginger tea, keeps me warm. I feel like it keeps my throat clear as well"* [Maryam, Interview 1]

According to Maryam, ginger tea (which is considered to be a herbal tea) was effective for keeping her body, or more specifically, her chest "*warm*". This enabled Maryam to remain in a 'dis- appearing' bodily state or possibly, 'eu-statis' (Leder, 1990; Zeiler, 2010). In Singh et al.'s (2002) study, South Asian groups used ginger to reduce inflammation and pain. According to Black et al. (2010), ginger can also be used to reduce muscle pain after exercise. This particular finding was based on a study with a relatively small sample size of young adults. Further, Black et al.'s (2010) study did not investigate the efficacy of ginger on any other types of pain, such as chest pain for asthma. Maryam's use of remedies that "*warm*" her body might be linked to her conceptualisation of asthma:

> *"I think I got it [asthma] gradually. I used to drink a lot of cold water whenever I'm cold with ice and stuff, so I used to have cough and cold, but still, I used to take anything like ice cream. I didn't use to care of my health"* [Maryam, Interview 1]

This account showed that Maryam believed that she was partly to blame for developing asthma. According to Weiss, Ramakrishna and Somma (2006), some traditions have asserted that illness was due to exposure to high or low temperatures. In Lakhanpaul et al.'s (2017) study, South Asian parents were reported to try and find different methods to treat their child's asthma. For example, some South Asian parents stated that they would adapt their child's diet as a form of asthma management (Lakhanpaul et al., 2017). This included avoiding cold foods, such as, ice cream, and providing the child with warm or hot foods instead (Lakhanpaul et al., 2017). In addition, and in line with the Ayurvedic system of healthcare, some South Asian families considered the 'hot' and 'cold' properties of different foods which might disrupt the physical and mental status of the body (Lakhanpaul et al., 2015). In the current research, Aisha used ginger and believed in its perceived efficacy:

> *"…they say if you've got asthma, ginger in your juice is good, so I always use that, put ginger in, I use turmeric and honey mixed together and that's good, that's really good…"* [Aisha, Interview 1]

> *"…you know what other thing is good, I don't like to do it too much because it's not very good, you could develop osteoporosis long term, cider vinegar for clearing the lungs"*
> [Aisha, Interview 1]

According to Aisha, the use of ginger, turmeric and honey helped Aisha achieve a 'eu-static' state (Zeiler, 2010). Additionally, cider vinegar was particularly "*good*" for *"clearing the lungs"* and contributed to 'eu-statis' (Zeiler, 2010). Aisha, however, indicated that cider vinegar can contribute to the 'dys-appearance' of the body if it was used in the long-term. When asked how she found these combinations, she replied: "*Research… Google on the net*" [Aisha, Interview 1]. It was not clear which websites Aisha browsed. This demonstrated that non-pharmacological treatments were not always influenced by cultural customs but by the perceived therapeutic efficacy of naturally-sourced ingredients and the potential for the body to remain in 'eu-statis' (Zeiler, 2010). Although Reena connected the use of turmeric, ginger and honey as South Asian traditions, Maryam and Aisha did not interpret their use of such ingredients in the same way.

Maryam and Aisha also embraced their 'Islamic' self, whereby they engaged in treatments embedded in their faith. Maryam and Aisha expressed their desire to utilise spiritual practices, which

were related to their Islamic faith. Maryam mentioned using water from Mecca which is considered to be holy. It was referred to as 'zamzam water':

> " *…whenever they [family members] go to Hajj [pilgrimage to Mecca], they bring the water, zamzam water [holy water], every time when somebody goes, they give us [zamzam] water, my mum comes fast and gives to me, [Maryam's mother] says: 'drink it, it may cure you', because zamzam cures disease as well, maybe that's why I don't have that worse feeling that people experience with asthma, maybe because of that"*
> [Maryam, Interview 1]

Zamzam water[15], or holy water, was a symbol of optimism for Maryam and her mother. It signified that there was hope for a cure for asthma, though currently there is no medical cure

[15] Zamzam water is located in Mecca, which is considered to be one of the most sacred places for Muslims (Abu-Taweel, 2017). The use of zamzam water has been cited in various holy scriptures, including the Quran, the Torah (Old Testament) and the Bible (Abu-Taweel, 2017). Zamzam water is considered to be 'holy water', and it is believed to be a gift from God (Abu-Taweel, 2017). Muslims use this water to help treat their illnesses, or in some cases, cure them of their ailments (Abu-Taweel, 2017). According to Khalid et al. (2014), zamzam water can be used to treat some illnesses. It is said to have anti-inflammatory properties (Khalid et al., 2014).

(see section 1.7). Maryam's account illustrated her mother's response to her daughter's asthma, who came "*fast*" to provide Maryam with the holy water, possibly hoping that the zamzam water would help cure her daughter of asthma. Although asthma is currently medically incurable, Maryam perceived that the holy water would benefit her. Believing that the zamzam water helped her, Maryam then engaged in an act of role distancing (Goffman, 1959) when she minimised the severity of her asthma. As quoted above, Maryam stated that she did not experience *"that worse feeling"* that others have with asthma because of the perceived power of the holy water.

Another practice that was oriented in Islam was the complementary method of cupping[16], which Aisha described in her interview: *"we do hijama [Arabic term for wet cupping]. They [cupping practitioner] cut and they draw the bad blood out*" [Aisha, Interview 1]. This suggested that there was good and bad blood in the body, and according to Aisha, the bad blood was extinguished from the body. It is possible that from Leder's (1990) and Zeiler's (2010) insights, the bad blood contributed to a 'dys-appearing' body, whereas the 'good' blood contributed an 'absent' body or 'eu-statis'. Cupping was done in order for the body to function effectively and to remain in a 'dis-appearing' bodily state of awareness (Leder, 1990) by getting rid of the 'bad blood'. From a medical perspective, cupping can act as physiotherapy for the chest (Clinkscale et al., 2012). In Maryam's and Aisha's view, zamzam water and wet cupping were perceived to contribute to 'eu-statis' (Zeiler, 2010).

Not all of the participants chose to use non-pharmacological treatments. Enayah explained that, although there were several non-pharmacological methods of treatment, she did not use these to help treat her symptoms: *"I know there's quite a lot of them around but I've never tried any, I just kinda stick to my prescribed inhalers"* [Enayah, Interview 1]. Jamal stated: *"I <u>don't</u> believe much of these home remedies. I'm <u>quite</u> a strong believer in medicine"* [Jamal, Interview 1]. As mentioned previously (see section 5.3; 'Managing medication'), Jamal was an 'accepter' because he accepted that he needed preventer medication. It is possible that he rejected the use of alternative treatments because he did not deny or distance himself from using Western medication. Others, including Priti, Samina and Indiana also questioned the efficacy of non-

[16] Cupping is a type of therapy, where heated cups are pressed onto the skin to create suction (Alrawi & Fetters, 2012). It is believed to stimulate the flow of blood and reduce inflammation and pain. In doing so, it rids the body of harmful substances (Alrawi & Fetters, 2012). The practice of cupping was recommended by the Islamic prophet, Muhammad (Alrawi & Fetters, 2012).

pharmacological treatments: *"I don't really like home remedies cos I don't know if it works or not"* [Priti, Interview 1]. Although Samina believed that such treatments were ineffective, her mother suggested the treatments to her nevertheless:

> *"…while I was ill, I have tried every Indian remedy known to mankind, apart from onion juice. I have had ginger, I have had lemon and honey, I had black pepper, I was made to chew raw cardamom, so many home remedies, you do not wanna know how I felt, I was made to chew raw ginger and keep it in my mouth, it was disgusting*" [Samina, Interview 1]

> *"My mum believed all of this and then she'd ring different [South Asian] people and they'd tell her different stuff, she'd be like 'oh why don't you try this, why don't you try that'. I'm like NO!"* [Samina, Interview 1]

In Samina's first account, she listed the various non-pharmacological methods of treatment she has been "*made to*" use to treat her ill health. In Samina's second account, she explained that she was only "*made to*" to use these remedies because her mother suggested that she tried non- pharmacological treatments. It seemed that there was a cultural expectation to try alternative treatments and in order to 'save face' (Goffman, 1963) in her South Asian community, Samina tried these various treatments. This was emphasised by Samina, who noted that her mother would contact other South Asian people, in order to gather more information about various alternative approaches. Samina's mother was born in Pakistan, where complementary therapies were commonly used to treat ill health (Hazir et al., 2002). Samina's accounts not only illustrated her frustration towards this type of treatment approach, they also showed that her treatment approach is negotiated with social influences, such as her mother and other members of her South Asian community. Applying Goffman's (1959) insights, Samina was forced to perform a role she was uncomfortable with when she was pressured to try non-pharmacological treatments. According to Goffman (1959), the 'realness' of a person's performance can vary. He discussed two types of behaviour within role performances; 'reality' and 'contrivance'. Goffman (1959) argued:

> "*We tend to see real performances as something not purposely put together at all being an unintentional product of the individuals' unself-conscious response to...a situation whereas contrived performances we tend to see as something painstakingly pasted together, one false item on another, since there is no reality to which the items*

of behaviour could be a direct response" (p. 70).

Samina explained that she performed this role for the sole purpose of pleasing her mother:

> *"…the only reason I take them is that if I don't take them, my mum will be like: 'see, I TOLD YOU and YOU DIDN'T LISTEN,' so, that's the only reason I take them, but I don't believe in any of them"* [Samina, Interview 1]

Using Goffman's (1959) analysis would suggest that Samina engaged in a 'contrived' performance of her 'South Asian' self when she tried several non-pharmacological treatments to please her mother. The performance was contrived because she did not believe in her role performance. For Samina, alternative treatments were associated with bodily 'dys-appearance' (Leder, 1990) rather than 'eu-statis' (Zeiler, 2010), as reflected in her comment: *"I refuse to believe any of them worked" [Samina laughs]* [Samina, Interview 1]. Nafisa explained that treatment approaches were often negotiated with other members of her South Asian community:

> *"…so, we [Nafisa and her mother] were told: 'oh you know, put a paan leaf*[17]*on with oil and it'll suck it all up and take a paper bag, put egg on it, heat it up, mirror heater, whack it on, and it'll take out all the phlegm and mucus from her chest', so we had that a lot when I was growing up"* [Nafisa, Interview 1]

In this account, it was evident that Nafisa was recommended to try various alternative treatments, which were perceived to help treat her asthma. Nafisa indicated that this was her South Asian community's way of helping:

> *"…everyone was always very more than overly helpful to come up with solutions, which might be cultural… but that's that their way of trying to help"* [Nafisa, Interview 2]

It seemed that there was a certain eagerness for other members of her South Asian community to be involved in Nafisa's asthma healthcare. Goffman's (1959) insights would indicate that following advice and trying out different alternative treatments was part of the 'normal' expected social order for someone who was 'South Asian' and coping with illness. Nafisa recounted an experience with some of these alternative treatments:

[17] Paan is a betel leaf (NHS, 2018d).

> *"…the paan I remember not having a problem with, paan leaf, cos it never hurt, but the paper bag would dry up, so the egg would, it dries up, so it'd crackle and STICK, so it would hurt, so I hated that"* [Nafisa, Interview 1]

Although Nafisa was happy to accept homeopathy and Tibb medicine as forms of treatment, she questioned the efficacy of using "*paan leaf*" and 'eggs':

> *"I don't know [if these treatments worked] cos I still had to go to hospital, so I don't think so. I remember when one of my kids was chesty and my naani [maternal grandmother] said to me: 'aah, do that same stuff, paan egg'. I was like: 'yeah, alright then' [sarcastically spoken] and I didn't do it"* [Nafisa, Interview 1]

When Nafisa was told to use traditional treatments by her grandmother, she engaged in a 'contrived' performance of 'South Asian' self, in order to 'save face'. Goffman (1963) argued that 'saving face' involved trying to sustain an effective impression of the self. Nafisa did this when she sarcastically agreed with her grandmother about trying out, what she called, "*paan egg*" methods. Her performance was 'contrived' (Goffman, 1959) because she agreed with her grandmother, yet, knew that she was not going to use these treatments.

Priti suggested that some South Asians did not use medical intervention because it was less preferable to non-pharmacological treatments: *"I don't really think they like it. I don't think they like taking tablets and medicine"* [Priti, Interview 1]. Medical intervention was, according to Priti, deemed untrustworthy by South Asians:

> *"I think it's because they don't know what it's in it, maybe, whereas home remedies, you make it yourself, so maybe that's why"* [Priti, Interview 1]

Priti described the perceived differences between pharmacological treatment and "*home remedies*". Since it was unclear about what went into medical treatment, it was believed to be untrustworthy. In contrast, "*home remedies*" were trusted because the people themselves made it and therefore knew exactly what they were treating themselves with. This illustrates the need for education about the usefulness of medical intervention for those who deem it untrustworthy.

5.4.1 Summary

To summarise, Reena, Nafisa, Aisha and Maryam used non-pharmacological treatment to help

treat their symptoms. In the current research, when applying phenomenologically-inspired insights from Leder (1990) and Zeiler (2010), non-pharmacological treatments, such as ginger, turmeric and honey were believed to contribute to a 'eu-static' bodily state (Zeiler, 2010). Moreover, for Maryam and Aisha, the use of some non-pharmacological treatments were embedded in Islamic tradition, including zamzam (holy) water and the practice of wet cupping, both of which were considered to contribute to 'eu-statis' (Zeiler, 2010).

Since the homeopathic approach contrasted with the Western-influenced medical paradigm, the use of homeopathy resulted in role conflict for Nafisa. When Nafisa visited her homeopathic practitioner, she was told to stop taking her inhalers. By applying Goffman's (1959) insights, it was argued that the role expectations of being an asthma patient conflicted with Nafisa's South Asian- influenced homeopathic user role. This led to Nafisa breaching the role expectations of her Western-influenced medical asthmatic role, where she was expected to take her inhalers regularly. It was also suggested that as part of Nafisa's pragmatist behaviour, she used alternative treatments to distance herself from using Western medication.

Some participants, including Samina, Enayah, Jamal and Priti, however, were not eager to use non- pharmacological methods. Using Goffman's (1959) analysis, Samina's and Nafisa's accounts suggested that they were involved in a 'contrived' performance of self when they were told to use various alternative treatments. Their accounts also showed that treatment approaches can be negotiated with other members of the community.

The findings have indicated that non-pharmacological approaches can be used in conjunction with pharmacological intervention. These alternative approaches can be an integral aspect of health management for some UK-resident South Asian adults with asthma. Therefore, HCPs need to be aware of this and acknowledge that patients may have different beliefs about treatment. Not all UK- resident South Asians with asthma in this sample however used non-pharmacological methods, and it is important not to assume that all UK-resident groups use such treatments, commensurate with Wen Jin et al.'s (2002) considerations. The next superordinate theme explores how some participants challenged other aspects of their South Asian culture and investigated some of the reasons why other South Asians did not engage in sport and/or exercise.

5.5 “Other South Asians are lazy”: Challenging cultural standards

As discussed in section 2.3.1, UK-resident South Asians - with asthma and in general - are less likely to participate in sport and exercise than other minority and majority populations in the UK (Jepson et al., 2012) and much of the evidence about sport and/or exercise has focused on the experiences of South Asians either without any reported illness (Rai & Finch, 1997; SportScotland, 2001; Carroll et al., 2002; Rishbeth, 2004; Openspace 2006; Jepson et al., 2008; Ahmad, 2011) or included those with diabetes (Lawton et al., 2006; Grace et al., 2008; Keval, 2009), coronary heart disease (Farooqi et al., 2000; Netto et al., 2006; Sriskantharajah & Kai, 2007) or obesity (Williams & Sultan, 1999) (see section 2.3-2.4). There is, therefore, a gap in knowledge about UK-resident South Asian adults with asthma and their experiences of sport and/or exercise.

Comments from Kalan’s Aisha’s, Dhaya’s, Lubna’s, Nafisa’s and Faheema’s interview transcripts led to this superordinate theme, which explores their perspectives about sport and/or exercise behaviour in the South Asian population. For Kalan and Aisha, there was a sense of frustration at the lack of motivation and low levels of sport and/or exercise participation from other South Asians. Nafisa, on the other hand, discussed why she believed South Asians did not take part in sport and/or exercise. Lubna considered the relational influences, who helped encourage her to engage in sport and/or exercise. Applying Goffman’s (1959) self-presentational insights, together with the SI perspective on role theory, Leder’s (1990) concept of the absent body and Zeiler’s (2010) notion of the ‘eu-static’ body, this superordinate theme explores the link between the South Asian cultural identity and sport and/or exercise participation.

The accounts from Kalan, Aisha, Dhaya, Lubna and Nafisa indicated that a sporting and/or exercising role did not fit with the role expectations of being ‘South Asian’. The term ‘role’ refers to the societal expectations and social scripts, which have been shaped by the collective beliefs of society (Georgas, 2006). In the current research, this refers to the expectations of the shared ideologies of South Asian society. In SI, roles are learned during social interaction; people interact with others and view themselves and others as occupying particular statuses (Georgas, 2006). In short, there are expectations associated with certain roles and role theory is about how someone should behave, based on their role expectations (Georgas, 2006). According to Georgas (2006), there are individual differences in each society about whether or not to agree with some role expectations. Some members of society might insist on the application of these role expectations, whereas, some members might be unorthodox and protest against their

societal expectations (Georgas, 2006).

In this superordinate theme, the participants believed that other South Asians were 'lazy' and did not participate in sport or exercise; it was not expected of them as 'South Asians' to be active. Thus, by engaging in sport and/or exercise, Kalan, Aisha, Dhaya, Lubna and Nafisa did not conform to their role expectations as 'South Asians'. Their accounts revealed that they challenged existing cultural standards and distanced themselves from the normative social order in South Asian society. A role, from the SI perspective, is not fixed or prescribed. Instead, it is something that is constantly negotiated between individuals. Nafisa explained the lack of participation from some South Asians:

> *"I think it comes from our culture… our parents had no time, it's not something that was ever in the lifestyle, you woke up, your priorities were praying, cooking, work and family events and the people that are still living very cultural, have a very cultural [South Asian] life, where they're constantly meeting the in-laws or feeding the in-laws. They don't have that concept of running or exercise in their lives anyway, cos their routines are just around family and work, that's it, their world does not expand beyond that [family]"* [Nafisa, Interview 2]

In this account, Nafisa explained that engaging in sport and/or exercise was not considered a priority for some South Asians. The notion of having an active lifestyle was unfamiliar to them because of their commitments to their families and their jobs. According to Nafisa, focusing on other priorities such as, "*praying*", "*cooking*", "*working*" and "*family events*" was considered a "*very cultural [South Asian] life".* Nafisa's account demonstrated that there are certain cultural role expectations to follow as part of the 'normal' expected social order and in order to live a *"very cultural [South Asian] life".* Some South Asians seemed to conform to these cultural role expectations. In SI terms, the 'South Asian role' consisted of "*praying*", "*cooking*", "*working*" and "*family events*" (as quoted above) and were considered appropriate behaviour for a South Asian person. Sport and/or exercise was not associated with this South Asian self. In Nafisa's view, those who continued to prioritise these commitments over sport and/or exercise were therefore perceived to live a *"very cultural life",* where they were "*constantly meeting the in-laws or feeding the in-laws*". For these South Asians, the "*concept of running or exercise*" was not relevant to them because *"their world does not expand beyond that [family]"* (as quoted above). According to previous research (Rai & Finch, 1997; Williams & Sultan, 1999; Farooqi et

al., 2000; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008; Jepson et al., 2008), one of the main personal barriers to physical activity for South Asian adults, was the increased emphasis placed on work commitments and working longer hours to financially support themselves in the UK. Other deterrents included the time constraints from other cultural priorities, such as familial obligations (Rai & Finch, 1997; SportScotland, 2001; Lawton et al., 2006; Jepson et al., 2008). According to Lawton et al. (2006), these deterrents affected South Asian women more than South Asian men because women have extensive cultural responsibilities and expectations placed on them after marriage (Lawton et al., 2006). Nafisa, however, did not indicate that there was a gender difference. It seemed that older generations were less likely to try and detach themselves from the 'South Asian' role. Kalan and Aisha perceived that other older South Asians in their communities failed to take accountability for their health and resisted participating in sport and/or exercise. When they compared themselves to other South Asians who did not exercise or play sport, Kalan and Aisha presented themselves as being atypical of this perception and unlike other South Asians. For example, Kalan was critical of others in his South Asian community who were unwilling to adopt health-enhancing behaviours, namely, engaging in sport and/or exercise:

> *"…my frustration is, I look at other colleagues that are South Asian, they're too lazy, they don't want that activity of sports on par with what I see with other communities, so when I go into the gym and it may be in a multicultural environment, there's gonna be less people of my generation there*" [Kalan, Interview 1]

Kalan, who is in his 50s and is a second-generation South Asian, stated that some South Asians of his generation distanced themselves from sport and/or exercise at the gym. He compared the levels of sport and/or exercise engagement with "*other communities*", which demonstrated to him that there was a lack of South Asians from his generation. Kalan suggested that "*colleagues*" who were South Asian were "*too lazy*" to adopt a healthy identity; one which comprised of an active lifestyle. Kalan, conversely, presented himself as an older South Asian who engaged in regular exercise, in contrast to 'other' South Asians: *"I'm in the gym fairly regularly, and I will do walking"* [Kalan, Interview 1]. It was unclear which South Asian communities Kalan was referring to in his accounts and who these 'South Asians' were that were deemed 'lazy'.

When people have to perform roles or associate with others that imply social identities different to that of the person's desired self-conception, they often try to distance themselves from those roles (Ferguson, 2015). Goffman (1959) argued that people's behaviour is not always bound by role expectations and thus, people do not embrace all aspects of the roles that they play. According to Stebbins (2013), Goffman's (1959) conceptualisation of role distance was at first too ambiguous to apply. Stebbins (2012) clarified Goffman's (1959) ideas and explained that role distance is associated with a particular status or identity, and reflects a person's desire to disassociate his/herself from the role expectations attached to the status or identity. The reason being the threat to self-conception, thus:

> *"…role distance has been defined as an attitude of dislike toward all or part of a set of role expectations which, when enacted, bring the threat of a loss of respect and at least momentary lack of support for one's self conception from certain reference others present in the situation"* (Stebbins, 1969, p. 69).

O'Brien (2019) observed acts of role distancing in young British male Muslims, who had been called to prayer. As male Muslims, they are required to attend the mosque for daily prayers. According to O'Brien (2019), when the call to prayer began, some of the males did not respond and entered the prayer hall intentionally late to differentiate themselves from the others who had responded and entered the prayer hall on time. O'Brien (2017) explained that the former would engage in acts, such as, playing on their phones, or going to the bathroom to deliberately waste time. This enabled them to distance themselves from the role of a 'good' Muslim (O'Brien, 2017). Therefore, these tactics were interpreted as acts of role distancing by O'Brien (2017, p. 58), which he discussed as, interactionally representing a difference between themselves and *"…the activity the incumbent would engage in were he to act solely in terms of the normative demands of someone in the position"* . Commensurate with O'Brien's (2017) application of role distancing, Kalan's account suggested that by deliberately engaging in exercise and visiting the gym, Kalan engaged in an act of role distancing when he differentiated himself from other South Asians of his generation. In short, he is 'unlike' other older South Asians because of his active lifestyle. From the SI perspective, Kalan negotiated his role as both a sporting individual and as an older 'South Asian' and challenged existing normative expectations by visiting the gym and participating in other forms of exercise, including walking.

Kalan continued to express his frustration at other South Asians who refrained from adopting a sporting and/or exercising role:

> *"…yet when I go out on the street they're all around me and they look, sad to say, unhealthy and overweight, so to me, they're not taking that health message on board and it doesn't take much to walk outside for 30 minutes, and the excuses you get for not wanting to go out for 30 minutes is quite amazing [spoken sarcastically]"* [Kalan, Interview 1

In this account, Kalan explained that other South Asians did not accept responsibility for their health. Together with his previous account, it seemed that Kalan suggested that other South Asians have remained passive to the idea of an active lifestyle because they are "*too lazy*" and are not "*taking that health message on board".* From Kalan's perspective, this presented an image of other South Asians as "*unhealthy and overweight*", or of other South Asians having 'dys-functional' bodies (Leder, 1990). His sarcastic tone at the end illustrated his frustration at the lack of motivation to "*go out for 30 minutes*". For Kalan, being active was considered appropriate behaviour with regard to his South Asian role, whereas for others, it was not. According to Leary (2019), who investigated self- presentational issues in sport, some people engage in sport and/or exercise to maintain the social identity of a 'fit' and 'healthy' person. It is possible that this was not a concern for 'other' South Asians, but it may have been for Kalan. In Netto et al.'s (2006) study (see section 2.3.1), for example, South Asian groups considered physical activity to be inappropriate, redundant and as something of no value to them. Aisha recounted an experience with her mother who was admitted to physiotherapy:

> *"…in the [South] Asian culture, if you've got a little bit of pain: 'oo I'll take a rest, I go to sleep' but <u>no,</u> it's the other way, you've gotta keep going, cos I know with my mum she became really really frail, her legs were really bad cos she discharged herself from physiotherapy"* [Aisha, Interview 2]

Aisha explained that in her culture, or "*the [South] Asian culture*", exercising was rejected in favour of "*taking a rest and going to sleep*". Aisha's account indicated that this was a culturally-influenced belief and suggested that her mother became much frailer because she discharged herself from physiotherapy. Commensurate with Aisha's view, her mother may have assumed that because she was in pain, she needed to "*take a rest*". Previous evidence has reported that South Asian groups held the belief that physical activity did not play a preventative role in

illness (Rai & Finch, 1997; Williams & Sultan, 1999; Lawton et al., 2006; Netto et al., 2006; Grace et al., 2008; Jepson et al., 2008). It was unclear, however, which South Asian groups the evidence was referring to. In the current research, this also seemed to be an issue. Like Kalan, Aisha referred to the 'South Asian' culture as though it is a homogeneous population, which seemingly insinuated that all South Asians share this belief. As previously mentioned by Singh (1994) (see section 1.9), South Asian communities should not be treated as a homogenous group.

In this superordinate theme, the participants did not refer to specific communities, rather, they indicated that the South Asian population was homogeneous in specific areas of life, such as, sport and/or exercise. This seemed to fit with the notion that being 'South Asian' had specific role expectations associated with it. According to Aisha, ideas of appropriate behaviour according to South Asian culture, included taking a rest instead of participating in exercise to help the body regain 'eu-statis' (Zeiler, 2010). This was evident for Aisha's mother, who seemed to believe that taking part in exercise was not considered to be helpful, commensurate with previous research (e.g., Rai & Finch, 1997; Williams & Sultan, 1999; Lawton et al., 2006; Netto et al., 2006; Grace et al., 2008; Jepson et al., 2008).

In terms of Goffman's (1959) insights, Aisha's mother was required to perform a 'physiotherapy patient' and an 'exercising' role, which mandated that she engage in regular physiotherapy. Since this contrasted with her 'South Asian' influenced beliefs, Aisha's mother discharged herself from physiotherapy. It seemed that Aisha's mother was resistant to physiotherapy because she believed that it would generate a 'dys-function' (Leder, 1990) instead of, 'eu-statis' (Zeiler, 2010) and was thus, resistant to adopting an 'exercising' role. According to previous literature (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah & Kai, 2007; Jepson et al., 2008), South Asian respondents have stated that physical activity was absent from their culture. It was demonstrated that South Asian groups considered physical activity as something borne out of 'Western' culture and uncharacteristic of their South Asian culture (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah & Kai, 2007; Jepson et al., 2008). The belief that physical activity was absent from South Asian culture was due to the limited childhood exposure to such activity when the respondents were young and lived in their country of origin. As a result, when they immigrated to the UK, physical activity was perceived to be a part of 'Western' culture instead of South Asian culture (Rai & Finch, 1997; SportScotland, 2001; Sriskantharajah & Kai, 2007; Jepson et al., 2008). Furthermore, physical activity was believed to be harmful to the body

(SportScotland, 2001; Netto et al., 2006). This was in complete contrast to research which has illustrated the benefits of having an active lifestyle, including reducing the risk of disease and improving physical function for people with asthma (Del Giacco, 2015) (see section 1.1). In the account above, Aisha dismissed the view that an active lifestyle, comprising of regular sport and/or exercise engagement was detrimental to one's health. Consequently, Aisha took her mother back to her physiotherapy sessions:

> *"…so, we [Aisha and her mother] went back and we said [to the physiotherapists]: 'no, she [Aisha's mother] needs to go on it [physiotherapy], look at her', and she [Aisha's mother] said that it's helped her, it's strengthened her legs and it's given her that strength. I said: 'I keep telling you that's what you need, you've gotta keep going'"*
> [Aisha, Interview 2]

In terms of SI, Aisha performed a 'facilitator/decision maker' role when she interacted with the physiotherapists to encourage them to re-engage with her mother. By engaging in physiotherapy, Aisha's mother needed to distance herself from what she previously believed to be correct and was required to adopt an 'exercising' role. After a period of physiotherapy, Aisha's mother experienced the benefits of active participation. In terms of Leder's (1990) and Zeiler's (2010) insights, Aisha's mother shifted from a 'dys-functional' body to 'eu-statis'; something she previously feared would not occur if she adopted an 'exercising' role. In order to for her to have achieved 'eu-statis' (Zeiler, 2010), however, Aisha's mother was facilitated to challenge the existing cultural standards by her daughter. According to Edgley (2016):

> *"…the character others impute to us depends on both an invisible structure of cultural conventions, social representations, and shared values, and a visible pattern of routinised joint action"* (p. 78).

In the current research, it seemed that sport and/or exercise behaviour was not part of the shared values of the traditional 'South Asian' role. Applying Goffman's (1959) analysis would indicate that both Aisha and her mother engaged in role distancing when they adopted a sporting and/or exercising role by disassociating themselves with the normative expectations required of them as 'South Asians'. Aisha reiterated the importance of active participation with her mother and suggested that regular exercise has helped improve her own asthma: *"I mean, look at me with my asthma, the last time I came to see you, and look at me now"* [Aisha, Interview 2]. This was in response to her first interview which was conducted the previous year,

where Aisha had suffered an asthma attack and was unable to exercise. Aisha reiterated throughout her follow-up interview that; "*You gotta keep fit*" [Aisha, Interview 2]. With her perspective on sport and/or exercise, Aisha was considered to be atypical of the attitudes other South Asians might have about adopting a sporting role. This included the perceptions that sport and/or exercise added no beneficial value, or that it caused further weakness and disease (SportScotland, 2001; Netto et al., 2006). Instead, Aisha's accounts resonated with the belief that sport and/or exercise participation improved physical function (as evidenced by Del Giacco, 2015) and enabled the body to remain in 'eu-statis' (Zeiler, 2010).

Since all of the participants in the current research self-identified as South Asian who participated in, or have previously taken part in some form of exercise and/or sport, it could be argued that they are all atypical of the belief that an active lifestyle bears no value (Netto et al., 2006). Using Goffman's (1959) analysis, it could be argued that all of the participants engaged in role distancing when they participated in sport or exercise; it acted as a way of them differentiating themselves from 'other' South Asians. As Goffman (1961, pp. 87-88) stated:

> *"A self… virtually awaits the individual entering a position; he need only conform to the pressures on him and he will find a me ready-made for him*".

This is why people might engage in role distancing. Goffman (1961, p. 105-110) advocated this as behaviours which are supposed to tell others, *"…do not attribute to me the kind of character this role would normally imply I possess".* In the current research, it was evident that Kalan, Aisha and Nafisa were differentiating themselves from 'other' South Asians. By repeatedly distancing themselves from the belief that exercise and/or sport was not beneficial, the participants were able to demonstrate a modern South Asian identity through repeated, embodied sporting behaviour. There is evidence, although limited in its scope, that some South Asians were aware of the health benefits of regular sport and/or exercise participation (e.g., Jepson et al., 2012; King & Little, 2017, see section 2.3.3). In an earlier study by Jepson et al. (2008), a generational difference was recognised; an issue touched on by Kalan:

> *"…in the younger generations, there is a reasonable mix [in the gym], but I'm talking about my generation, so we're talking a plus fifty brigade, you may see one or two [South Asians], but when you look in the gym, there's lots of other older White men and women that are exercising*" [Kalan, Interview 1]

Kalan explained that younger South Asians were more likely to attend the gym, whereas his

generation were much less likely to be seen in the gym. Yet, according to Kalan, there were *"lots of older White men and women"* present. This indicated that there was a paradox between the younger generation and older generation within South Asian groups, as well as a stark difference between the older White group and older South Asians in terms of exercise participation in the gym. As Kalan stated, this was associated with their cultural background, since there were *"lots of other older White men and women that are exercising".* Later in the interview, Kalan argued that older South Asians 'chose' not to visit the gym: *"…there should have been more South Asian people, but they just choose not to come there*" [Kalan, Interview 1]. Using Goffman's (1959) analysis would suggest that older generations were less likely to detach themselves from their role expectations as traditional 'South Asians' and adopt a sporting role in the gym. Dhaya suggested that there was more emphasis on 'looking' healthy in her South Asian community, than acting healthy: *"I think it's more <u>emphasis</u> on <u>looking</u> healthy then actually <u>being</u> healthy"* [Dhaya, Interview 1]. Dhaya and Faheema, who were part of a younger generation, elaborated on this:

> *"…in Asian communities, they think that: 'oh, it's <u>fine,</u> you can eat what you want, you don't really need to exercise, it's good to be <u>round</u>. Older generations still do things like that like: 'oh, you should eat all this and everything and it's like <u>no!</u> It's not good"* [Faheema, Interview 2]

> *"I think for <u>me,</u> it's more about <u>being</u> healthy. If you're healthy, then you're obviously healthy but I think with a lot of [South Asian] <u>people,</u> they'd be like: 'oh, look, you're <u>not</u> healthy enough, you're too <u>skinny,</u> you're too this but <u>that</u> is kind of healthy. I think they think of it [as if] that person <u>looks</u> healthy, rather than they actually are"* [Dhaya, Interview 1]

Here, it was evident that Dhaya and Faheema perceived that other South Asians were more concerned about a person's appearance. According to Faheema, other South Asians believed that it was *"good to be round"* and endorsed a fuller body type. Dhaya shared a similar perspective when she mentioned that being skinny was not perceived to be 'healthy' in her South Asian community. In terms of self-presentation (Goffman, 1959), it involved projecting a self-image which was personally beneficial. According to Dhaya, the presentation of one's South Asian self was related to conveying a persona of 'looking' healthy. If he/she looked the part, in this case, 'round', or not too skinny, it seemed that they were more likely to fit into South Asian

society. Both Dhaya and Faheema challenged existing cultural standards when they contradicted this view and their sarcastic tone illustrated their feigning attitude towards 'other' South Asians. Dhaya proposed that the younger generation of South Asians did not conform to the traditional 'South Asian' role and were more health-conscious:

> *"I think it has changed. I think younger people are considering their health more and more. I think a lot of [younger] people, even at this university, you see they do go [to the] gym and they do exercise and watch what they eat to a certain extent, whereas I think maybe the other generations don't do that or they didn't do that*" [Dhaya, Interview 1]

Similarly, to Kalan, Dhaya explained that there was a generational difference between the younger and older generation of South Asians. According to Dhaya, the younger generation were health- conscious and were more likely to integrate a sporting role with their South Asian role. In the current research, it was evident that older and younger generations did not conform to their societal role expectations as 'South Asians'. For Kalan and Aisha, in particular, being part of an older generation of South Asians where sport and/or exercise was not considered appropriate behaviour or part of the cultural norm meant that they detached themselves from their societal role expectations of older South Asians. In the following account, Lubna discussed how her parents who were part of the older generation, encouraged her to be active:

> *"I grew up in a very different environment to a lot of South Asian families, my parents are born and raised here [in the UK], my dad swims, my mum likes to play badminton and so they've always encouraged me to try to play sports or do some form of exercise to stay healthy and to stay fit, so I think that was quite important to them because they were also driven by society to do exercise and sports so [it] influenced the way I grew up as well"* [Lubna, Interview 1]

Lubna described how she was socialised to engage in various sports, though, she suggested that this was because she "*grew up in a very different environment*"; one where her parents were born in the UK and were physically active. This made her parents different to 'other' South Asians who were not born in the UK. It seemed that Lubna's parents were distancing themselves from their South Asian cultural role and re-negotiating their roles as British South Asians, where they were "*driven by society*" (as quoted above) to exercise. This implied that they incorporated an active lifestyle because it was perceived to be a part of British society. According to Leary

(2019), people can engage in sport and/or exercise for self-presentational reasons, such as, being seen as physically active or 'fit and healthy' in other peoples' view. The latter, however, was unclear and would require Lubna's parents' perspective for clarification. Engaging in sport seemed for them, to be in contrast with the 'cultural way of life', previously proposed by Nafisa. It might also be why Lubna explicitly stated that she was born in a "*different environment to a lot of South Asian families*". Further, Lubna's account indicated that her parents engaged in role distancing (Goffman, 1959) from 'other' South Asians, by challenging the existing 'South Asian' cultural standards when they engaged in sport. Although Lubna's parents were "*driven*" by society, Lubna was influenced by her parents to take part in sport and exercise, emphasising the role of the micro social order. Using the SI perspective, it could be argued that sport and exercise held symbolic meaning for Lubna, who learned from her parents how to integrate a sporting role with her South Asian self. Additionally, Lubna explained that she was encouraged by her parents to engage in sport and/ or exercise to help manage her asthma:

> *"…when I was growing up, I had to do a lot [of] exercise, my parents encouraged me to do a lot of exercise so cross country and stuff. I have the theory that it [asthma] got better as I was doing more exercise and I'm always pushing my body, so I feel like my lungs and everything got a bit stronger just doing exercise"* [Lubna, Interview 1]

In this account, Lubna discussed how sport and/or exercise helped her to strengthen her body, or more specifically, helped to strengthen her lungs. This was an example of how Lubna challenged her existing South Asian cultural standards in order to manage her asthma. Her parents were integral to helping her challenge these standards. This also contradicted with the belief that physical activity, including sport and/or exercise, was harmful to the body, as reported in the results of SportScotland's (2001) and Netto et al.'s (2006) studies. Aisha's account provided another example of someone who believed sport and/or exercise helped her to manage her asthma:

> *"…if I don't swim on a regular basis, then my asthma gets worse. Swimming really helps me to breathe and to keep my asthma in check. I walk a lot, so I have to keep fit"* [Aisha, Interview 1].

Aisha incorporated swimming and walking as a management strategy, which suggested that it might be significant for some South Asians with asthma to engage in role distancing (Goffman, 1959) by integrating a sporting role with their South Asian self, in order to improve their health.

5.5.1 Summary

In summary, the participants in this superordinate theme presented themselves as being atypical of other South Asians and distanced themselves from culturally-influenced beliefs about sport and/or exercise. The accounts provided by Kalan, Aisha, Dhaya, Nafisa, Lubna and Faheema directly challenged previous evidence (e.g., SportScotland, 2001; Netto et al., 2006) and their existing South Asian cultural standards when they engaged in an active lifestyle.

Other South Asians, particularly older generations, were perceived to lead their everyday lives in line with cultural role expectations, such as, cooking and family commitments. Kalan acknowledged that there was a generational difference in terms of sport and exercise participation and presented himself as an active, sporting South Asian. When applying Goffman's (1959) insights, it was evident that Kalan engaged in role distancing when he compared himself against other South Asians and was critical of his non-sporting peers. This also illustrated the changing landscape of South Asians' participation in sport and/or exercise. Aisha influenced her mother to integrate an 'exercising' role with her South Asian role, in order to improve her health. This meant that Aisha's mother needed to distance herself from the existing cultural standards, and the view that an exercising and/or sporting role was not appropriate behaviour for South Asians. Further, Nafisa's accounts indicated that she was detaching herself from what she termed, the "*South Asian side".* It could be argued that all of the participants in this research distanced themselves from their South Asian role, since they all participated in sport and/or exercise at some point in their lives. In the participants' accounts, it seemed that it was about working with roles, which are not attached to fixed expectations.

Overall, this superordinate theme has revealed that a change in thought about sport and/ or exercise was taking place, where previous conceptions about sport and/or exercise were being challenged. This included the notion that sport and/or exercise was harmful to the body (see SportScotland, 2001; Netto et al., 2006), and that it created 'dys-function' (Leder, 1990). For Lubna and Aisha, an active lifestyle, including swimming and cross country running, was believed to strengthen their physical condition and asthma. Thus, sport participation was used as an asthma management strategy. This leads to the next superordinate theme, titled; 'Managing sport and exercise', which explores the ways participants manage sport and exercise, including the types of activities they choose to engage in.

5.6 Managing sport and exercise

As discussed in section 1.1, susceptible individuals and people with asthma often experience symptoms such as breathlessness and tightness of the chest when they engage in sport and exercise (Del Giacco, 2015; NHS, 2018). Asthma UK (2019a) recommends people with asthma to engage in exercise and sport, however, this is often difficult when symptoms of asthma occur. Participants described their experiences of sport and/or exercise, which led to the superordinate theme of 'Managing sport and exercise', which was about how they learned to integrate sport and/or exercise into their everyday lives. Participants mentioned management techniques, such as, analysing their body's capabilities and acknowledging their physical restrictions. Theoretical insights from Goffman's (1959) presentation of self, as well as Leder's (1990) concept of the 'dys-appearing' body, and Zeiler's (2010) notion of the 'eu-static' body were used to inform this superordinate theme.

Participants' comments about sport and/or exercise resulted in two subordinate themes within this superordinate theme. The first subordinate theme; 'Finding the right balance' (see section 5.6.1) focused on how participants manage the presentation of their asthma and sporting-self by experimenting with different forms of exercise and sport. The use of an inhaler during exercise and/or sport acted as a 'marker' of an 'unsuccessful', or 'undesired' (Goffman, 1959) performance of the sporting-self. The second subordinate theme; 'Feeling self-conscious' (see section 5.6.2), provided an analysis of the participants' strategies for maintaining an effective presentation of their asthma and sporting-self. According to Goffman (1963), the effective maintenance and control of the body and self requires a particular level of ability and competency. For the participants in the current research, this related to the ways in which they attempted to manage their asthma during sport and/or exercise, to avoid displaying their physical discomfort to others.

5.6.1 Finding the right balance

In his book, 'Self-presentation: Impression management and interpersonal behaviour', Leary (2019) explained that the sporting activities people choose to do have self-presentational implications. This subordinate theme; 'Finding the right balance', explored the ways in which Maryam, Enayah, Indiana, Jamal, Kalan, Reena, Priti, Samina, Lubna and Tasneem attempted to work out which types of exercise and sport helped them to achieve their sporting goals. This fit with Goffman's (1959) insights on what he called, performing an 'idealised' performance

(Goffman, 1959). In the current research, an 'idealised' performance related to sporting performances which were not disrupted by the asthma-body-self. In the present study, participants' accounts suggested that an idealised performance of the asthma and sporting-self included distancing oneself from his/her inhalers during sport and/or exercise and working out how to keep the asthma-self hidden from others during participation. When the asthma-self was concealed from others during sport and/or exercise, the participants could 'pass for normal' (Goffman, 1963). Additionally, this subordinate theme investigated how the asthma-body appeared to the participants in different ways during sport and exercise participation by applying Leder's (1990) concept of the 'dys-appearing' body and Zeiler's (2010) notion of the 'eu-static' body.

Maryam described how she tried to find her rhythm and her steady state:

> *"…because of my asthma, at that time, it used to affect me, I can't do speed, or I can't run faster because I will be out of breath, so I used to do a steady way, running but steadily, so that I can continue exercising. If I have to do it [exercise] fast, then I just used to get out of it [breath] in ten minutes maximum, but when I do [it] steadily, slowly then, twenty minutes, half an hour, or one hour, it's okay*" [Maryam, Interview 1]

After learning to accept that she "*can't do speed*" because of her asthma, Maryam tried to find a sporting rhythm, which allowed her to remain in 'eu-static' bodily state, that is, when the body appeared to her as 'good', or 'well' (Zeiler, 2010) (see section 3.5.2). She specifically stated that her body would appear to her as 'breathless' if she went "*fast*". It seemed that she cultivated the skill of learning how to steady her body by going slow, where she was able to feel a perceived sense of control of her body during exercise. After an uninterrupted period of exercise, her asthma-body appeared to her as 'eu-static' (Zeiler, 2010), when she felt "*okay*". Later, Maryam suggested that she refrained from engaging in activities that were health-damaging to her:*"…exercising is not making me to get an asthma attack, unless I'm doing something wrong, doing something that my body can't do"* [Maryam, Interview 1]. Other participants, including Enayah and Indiana discussed how they alternate between different forms of exercise to find the right balance:

> *"…when I'm doing a jog, I attempted that last year, but even fast paced walking after 10, 15 minutes, I tend to feel my chest is getting a bit tight now and I need to kind of*

slow down and pace down and before I know it, it's [chest] pumping" [Enayah, Interview 1]

"…and it's [jogging or fast paced walking] stopped in the fear that I don't wanna let it get to a point where I won't stop without using the inhaler or take a nebuliser" [Enayah, Interview 1]

Although Enayah was one of the participants who used her medication regularly (see section 5.3; 'Managing medication'), she spoke about her inhaler differently in the above accounts. Here, Enayah explicitly stated that she stopped jogging or fast paced walking, in order to refrain from using her inhaler or her nebuliser. This indicated that Enayah distanced herself from using the inhaler during exercise. It is possible that the inhaler was perceived as a 'marker' and a reminder of her asthma- self, thus performing exercise without using the inhaler was considered to be part of an 'idealised' performance (Goffman, 1959) of Enayah's sporting-self. Indiana elaborated on this:

"I don't tend to run cos I find that my asthma gets brought on a <u>lot quicker</u> if I run, <u>even</u> say if I'm at the gym and I'm on the treadmill, I will <u>always</u> walk, I will <u>never</u> try to run because I know that <u>after</u> five minutes, it will just tire me out too much" [Indiana, Interview 1]

"…if I needed to run, I'd find it quite difficult to run and still be okay at the end, I'd need to use my inhalers almost all the time" [Indiana, Interview 2]

Evidence has suggested that running in particular, can trigger symptoms of asthma for susceptible individuals and can be a barrier for some people with asthma (Del Giacco, 2015). In Indiana and Enayah's case, trying to run or jog was challenging and could not be achieved without symptoms appearing. Commensurate with Leder's (1990) notion of the 'dys-appearing' body, running or jogging descended into bodily 'dys-appearance', that is, the body appeared as 'bad' or 'unwell' to Indiana and Enayah. For Indiana, this occurred when she began to "*tire*". She knew that her body would 'dys-appear' (Leder, 1990) after five minutes. This also illustrated how quickly symptoms affected sporting progress. Due to the difficulties she experienced when she ran, Indiana explained that she would have to use her preventer and reliever inhalers several times. Although, this would not help unless it was in her system. The BTS (2016) asthma guidelines state that the preventer inhaler should be used as regular therapy and not to manage

oncoming symptoms. Instead, the reliever inhaler should be used to treat symptoms when they occur, and it is recommended that the reliever inhaler is used 15 minutes prior to exercising or sport participation (BTS, 2016). Indiana and Enayah did not mention this. Similarly, to Enayah, Indiana seemed to prefer engaging in activities that did not require the excessive use of her inhalers. Sporting activities which required an inhaler were not attempted, for example, Indiana stated that she "*never*" ran. Instead, she preferred walking:

> *"I <u>like</u> walking cos it takes you away from normal busy life, I don't usually <u>feel</u> like I need the inhaler until half an hour into it, so I <u>can do</u> something without it being too much of a strain"* [Indiana, Interview 1]

Although walking still required an inhaler, Indiana enjoyed walking. This was because it *"takes her away from normal busy life".* In Zeiler's (2010) terms, walking enabled the body to remain in a 'eu- static' and positive state and did not disrupt intentionality. This meant that the body did not appear to Indiana as a hindrance (Zeiler, 2010). According to Zeiler (2010, p. 8), where the *"dys-appearance' of the body* (Leder, 1990) *implies discomfort, the 'eu-appearance' of the body implies comfort and harmony"*. In cases of eu-appearance, "*the mind-body-world unity is in harmony*" (Zeiler, 2010, p. 16, see section 3.5.2). In the extract above, Indiana viewed walking as a form of relaxation rather than as a sport. During her walk, Indiana's mind-body-world unity remained intact for approximately "*half an hour*", before she began to feel a "*strain*" on her body. When this happened, she became aware of her asthma-body-self and used her inhaler. In another extract, she explained that she would:

> *"…go for a walk and it'll like help to calm me down, rather than me walking towards a goal. It's kind of just walking to de stress"* [Indiana, Interview 1].

Others tried to find the right sporting balance by negotiating the intensity of their sport and/or exercise, in order to minimise symptom disruption and remain in 'eu-statis' (Zeiler, 2010). Reena provided an example of this:

> *"I haven't put myself under that amount of stress. I think if I was to start doing the sprinting and the running, I <u>would</u> need my pump. If I was to do, I've forgotten what it's called now, it's a certain form of training where you do 30 seconds really rapid, you go back one minute not rapid, 30 seconds rapid, if I did that, I know I would need my pump, there's no if's or but's about it, my recovery would be a lot slower"* [Reena, Interview 2]

In Reena's account, it was clear that she chose not to place herself in a position where her sporting progress was threatened by her asthma-self. She recognised that if she was to place further pressure on herself to take part in "*rapid*" training, her sporting performance of self would be interrupted by her asthma-self, acknowledging that she would require an inhaler. A form of training which required "*rapid*" movements would negatively affect Reena and take longer for her to shift from bodily 'dys-appearance' to 'eu-statis' (Leder, 1990; Zeiler, 2010). Up to now, the accounts provided by Maryam, Enayah, Indiana and Reena have suggested that they tried to find the right balance by finding specific types of sporting activities, which helped them to remain in an 'absent' or 'dis-appearing' bodily state (Leder, 1990) and enabled them to reduce the use of their inhalers. A 'dis-appearing' state of awareness is when the body is 'absent' from conscious awareness, where it remains in the corporeal background (Leder, 1990). In complete contrast, Jamal integrated different elements of exercise into his workout routine. He described how he enjoyed weight training because his asthma-body-self did not threaten his performance of sporting-self in that domain:

> *"…for about fifty minutes, go do about twenty five minutes on the running machines, go on a few more cardio, and then on weights, that's the sick [good] thing about weights, it don't matter if you have asthma or not cos that's more strength training, it's to do with your breathing and you're gonna have to breathe in and out, but it's not gonna strain your lungs as much, so it don't matter what you're doing with weight and I won't need to use my [reliever] inhaler"* [Jamal, Interview 1]

Similarly, to Indiana, Enayah and Reena, Jamal sought to reduce the use of his reliever inhaler during participation. Weight training in particular, allowed him to distance himself from using his inhaler mid-performance. This was presumably because weight training limited respiratory and cardiac effort (Legg-Ditterline et al., 2018). Also, during weight-training, Jamal was aware of his body as 'well' and 'good' (Zeiler, 2010). He compared his weight training performance to a cardio routine:

> *"…but whenever I'm on a cardio machine I've always kind of got that worry, 'am I getting wheezy now?', 'am I starting to cough?' and obviously that's gonna set you back a bit, cos you gotta then stop what you're doing, take your inhaler"* [Jamal, Interview 1]

In contrast to weight training, his cardio performance revolved entirely around his breathing

ability because of the increase in respiratory effort. In Jamal's previous account, he indicated that his asthma-body remained in the background of conscious thought during weight training, whereas it was firmly at the forefront of his mind when he was participating in cardio. When he was forced to use his inhaler mid-performance, Jamal suggested that his sporting progress and performance of sporting-self was interrupted. Thus, it seemed that experiencing symptoms of asthma mid-performance disrupted Jamal's mind-body-world unity (Zeiler, 2010), as he became more focused on his asthma-body and his symptoms, instead of his cardio performance. On the other hand, when he could perform without using the inhaler mid-performance, as he did during his weight training, he was able to present an 'idealised' performance (Goffman, 1959) of his sporting-self. Similarly, to Enayah, Indiana and Reena, taking the reliever inhaler mid-performance might be considered a 'marker' of an undesired performance of the sporting-self for Jamal. Like Jamal, Kalan seemed to enjoy pushing himself in the gym and participating in exercise for prolonged periods of time with minimal disruption from his asthma-body-self:

> *"…it's an immediate relief response to that thing [asthma] and I know I'm going to have it [asthma] anyway, so you may as well prepare for it, then you know when you're exercising, it's not an issue. I suppose some people may decide to go on a treadmill and wait until they feel wheezy, but I want relief ahead of time, so I can do quite an extensive amount of exercising"* [Kalan, Interview 1]

In Kalan's account, it was evident that the reliever inhaler was used as a form of pre-dosing, as recommended by Asthma UK (2019a) and the BTS (2016) guidelines. Kalan 'prepared' his asthma-body-self by using his reliever inhaler before exercising, so that his symptoms did not disrupt him mid-performance. Applying Goffman's (1959) self-presentational insights would indicate that pre-dosing with the reliever inhaler acted as a 'defensive practice' (Goffman, 1963, p. 25). Defensive practices are used when individuals seek to protect their performance of self (Goffman, 1963). For Kalan, the use of the reliever inhaler became part of a "*pre-established pattern*" (see Goffman, 1963, p. 27), which was routinely performed when he engaged in exercise, allowing him to 'pass as normal' (Goffman, 1959). It is possible that pre-dosing with the reliever inhaler was used as an intentional tactic by Kalan to sustain his desired impression of sporting-self and enabled him to physically challenge his body. Kalan described what happens when he forgets to pre-dose with his reliever inhaler:

> *"…should I've forgotten, it does happen on occasions, if I go on the treadmill, I do know*

> *I'm limited as to how much I'm gonna push myself, so yeah it is noticeable, and I tend to become slightly, NOT overtly wheezy, but do tend to struggle and I just don't feel I can push myself much, whereas if I'd remembered to take my Ventolin [reliever inhaler] before I go into the gym, that's fine, I'm more than happy to carry on"* [Kalan, Interview 1]

Pre-dosing with his reliever inhaler enabled Kalan to prevent some of the potential negative consequences associated with the asthma sporting body-self. It allowed his asthma-body to remain 'absent', or in a 'dis-appearing' bodily state (Leder, 1990). When he forgot to use his reliever inhaler, Kalan explained that he was "*limited*", and that his asthma-body became "*noticeable*". Using Leder's (1990) insights, this would indicate that Kalan's asthma-body began to 'dys-appear'.

The appearance of a 'dys-functional' body (Leder, 1990) made Kalan question how well he could perform if he was to "*push*" himself in the gym. Pre-dosing with the reliever inhaler enabled him to enact an 'idealised' sporting performance of self without the threat of the 'dys-appearing' body (Leder, 1990). A successful, or 'idealised' sporting performance of self, seemed to be perceived by the participants as one which helped them to remain in an 'absent' (Leder, 1990) or 'eu-static' bodily state (Zeiler, 2010). Enayah explained this in further detail: "*…when I'm feeling well, it's the swimming, cos I tend to find I've got more support in the water"* [Enayah, Interview 1].

> *"…I don't have that where I'm panty and feeling out of breath and, 'oh I've gotta stop, I've gotta stop'. With other exercise, I tend to find, I can't do more than 5, 10 minutes without feeling, 'oh, [whispers] I can't do this'"* [Enayah, Interview 1]

With regard to a form of embodiment where the body is in a taken-for-granted state of corporeal 'disappearance' from conscious awareness (Leder, 1990), Enayah learned that swimming permitted her to remain in a 'dis-appearing' bodily state. This was only the case when her body first appeared to her as 'well' (Zeiler, 2010). Enayah indicated that when she felt "*panty*" and "*out of breath*", her sporting sense of self was diminished, where she believed that she could not engage in exercise. As previously mentioned, an 'idealised' sporting performance of self for Enayah might be one that is typified by remaining in a 'eu-static' (Zeiler, 2010) or a 'dis-appearing' (Leder, 1990) bodily state of awareness. Additionally, Enayah stated that swimming was particularly effective for her lung function, giving rise to an experience of the

'absent body' (Leder, 1990); *"it's not so bad and my lungs feel a lot better"* [Enayah, Interview 1].

Others were forced to acknowledge their physical restrictions after experiencing an asthma attack after exercise. Priti described how the experience of an exercise-induced asthma attack prompted her to learn about her asthma-body:

> *"I was going to the gym a lot. That week, I went there the whole day of the week, so I think that's what… triggered… the asthma attack"* [Priti, Interview 1]

> *"I think my muscles was feeling tiring and especially, my chest and back were really hurting, my muscles really hurt, not sure why, it just really hurt, after I did my cardio, it really hurt"* [Priti, Interview 1]

When Priti reflected on her asthma attack, she contemplated why she was experiencing pain and fatigue. She realised that she was experiencing an exercise-induced asthma attack; *"I couldn't sleep because I couldn't breathe properly, and then my chest really hurt, it felt really tight, and then I started wheezing"* [Priti, Interview 1]. In cases of bodily dys-appearance, Merleau-Ponty (2002) argued that individuals attend to their bodies as thematic objects of experience and they move into a state of reflective bodily self-awareness. In essence, their attention is directed towards their body to help them understand more about their "*bodily feel*" (Zeiler, 2010, p. 4). It also reminds them of their restricted capabilities (Leder, 1990). Commensurate with Merleau-Ponty's (2002) insights, Priti used her experience of an asthma attack to learn about her "*bodily feel*" (Zeiler, 2010, p. 4) during exercise; *"I think I'll do it, lesser than before"* [Priti, Interview 1]. For Priti, finding the right balance was related to learning about her physical limits and learning how "*far*" she could potentially go when she exercised: *"…limits yeah, I think I wouldn't want to know how far"* [Priti, Interview 1]. In her follow-up interview, Priti suggested that she needed to "*build up*" her exercise tolerance:

> *"…it was really painful when running, but with walking, it's easier and I think I just need to build up, need to constantly walk, instead of stopping and then starting it"* [Priti, Interview 2]

When her body was in pain, it gave way to a 'dys-appearing' bodily state (Leder, 1990). Priti learned which exercises were "*painful*" for her body and recognised which exercises were "*easier*" for her and substituted running for walking. Where in the previous extract Priti seemed

to be unsure about why her muscles were "*tiring*", here, she had a clearer idea about her pain. It might be that for Priti, her 'idealised' performance (Goffman, 1959) of sporting-self involved building up her exercise tolerance and learning about which types of exercises were suited for her asthma-body, in order to perform a successful performance of sporting-self and keep her asthma-body-self concealed. When she adapted her approach to exercise to include walking, she developed a positive sporting sense of self, which enabled her to enter 'eu-statis' (Zeiler, 2010), or in her words, a *"much more nicer"* bodily state of awareness; *"I'm taking it more chill and just doing walking which is more nicer for me"* [Priti, Interview 2]. Similarly, to Priti, Samina and Lubna explained how they were building up their exercise tolerance levels after experiencing injuries and/or asthma attacks. Samina described how she was taking "*baby steps*" to recover her exercise tolerance:

> *"…my exercise tolerance has dropped since my attack. I struggle to go up a flight of stairs, which I'm trying to improve in baby steps, but before when I came in, I'd go in from the car to my class, was just horrible going up and down, at home was horrible as well, so I slowly tried to, as the days went by, do more and more and more"* [Samina, Interview 1]

When Samina experienced an asthma attack, her exercise tolerance dropped. In her account, Samina described how this led to her struggling to walk up a "*flight of stairs*", and how "*going up and down*" was "*horrible*" for her. For people without respiratory illness or any other form of illness that affects respiratory performance, walking up and down a flight of stairs may be considered a taken-for-granted task. Whilst "*going up and down*" or going *"from the car to class*", Samina was experiencing a 'dys-functional' body (Leder, 1990). In order to recover, Samina explained that she was trying to do "*more and more and more*". This would enable her to experience either a bodily state where her body remained 'absent' (Leder, 1990), or 'eu-static' (Zeiler, 2010), instead of one which was making her feel "*horrible*". In an attempt to improve her sporting body-self, Samina started participating in Zumba, which is an exercise fitness program characterised by fast paced dance and aerobic movements and performed to energetic music (NHS, 2016):

> *"…I started going Zumba about four weeks ago now. First class, I was out every five minutes taking my inhaler, but now, I only take it before and once in the middle and I'm okay, so it's okay, it's getting better"* [Samina, Interview 1]

When Samina first started her Zumba class, she stated that she was "*out every five minutes*" taking her inhaler. This resonated with previous accounts by Indiana, Enayah, Jamal and Reena, who suggested that taking their inhalers mid-performance interrupted their exercising and/or sporting progress. The excessive use of her inhaler implied that Samina could not engage in Zumba without using her inhaler to recover. When she explained that she was "*getting better*", she related this to the number of times she used her inhaler, as well as the time periods at which she used her inhaler. An 'idealised' performance for Samina then, was comparable to Indiana's, Enayah's, Reena's and Jamal's accounts, who indicated that they tried to distance themselves from using their inhalers mid-performance. Samina's account also demonstrated that she used her inhaler before Zumba as a form of pre-dosing, allowing her to engage in Zumba with less interruptions from her asthma. Similarly, to Kalan, pre-dosing was used as a 'defensive practice' (Goffman, 1963) by Samina to conceal her asthma-body-self, which in turn, allowed her to 'pass as normal' during Zumba. Like Samina, Lubna described engaging in "*baby steps*" in order to recover her exercise tolerance level after experiencing an injury:

> *"…baby steps. I wouldn't directly put myself on the start from not doing exercise to doing really intense exercise. I don't think that'd be good for my breathing at all"* [Lubna, Interview 1]

> *"…I would start from doing maybe, try and do just a small job and then try and raise it, start running, sprinting, just get everything a little bit further and further each time, maybe increase it every month or, every two months, so that's the way I did it, cos I didn't wanna start off with the intense and <u>then</u> struggle breathing"* [Lubna, Interview 2]

Unlike Priti and Samina, Lubna explicitly discussed how her approach to exercise and/or sport was developed to protect her breathing ability. Thus, she implemented a process that involved engaging in "*a small job and then try and raise it",* in order to decrease the chances of experiencing a 'dys-appearing' body (Leder, 1990). In Lubna's case, a 'dys- appearing' body (Leder, 1990) occurred when her mind-body-world unity was disrupted and she struggled to breathe (Leder, 1990). Tasneem discussed a similar situation to Lubna and described how dance seemed to be an important part of her sporting-self:

> *"I used to participate in everything. I was part of a dance group, I do breakdancing, street dancing and I <u>had</u> to <u>drop out</u> of <u>dance as well</u> and I'm <u>really</u> passionate about*

dance. Dance is <u>all</u> I live for, I love dancing, so I had to drop out of that for a while" [Tasneem, Interview 1]

Tasneem stated that dancing was a passion, and that her dancing self was threatened by her asthma-body-self. She immediately disclosed that she could now participate in dance and other sports because of her perceived sense of control of her asthma-body:

"<u>Now</u> I can <u>dance,</u> I can play football and I can control it. I <u>know</u> my limits when I need to stop and need to take a break…now if I feel it [asthma] coming, I can't breathe or feel isolated, I'll take my [reliever] inhaler <u>first,</u> then I'll sit down, I'll take a break. I'll breathe in, breathe out, exercises like that" [Tasneem, Interview 1]

As previously mentioned (see section 5.2; 'Negotiating the asthmatic identity'), Tasneem explained that, as long as she knew how to control her asthma-body, she could participate in dance and football. Here, Tasneem seemed to gauge an understanding about how to control her asthma-body during sport. She believed that she understood what her "*limits*" were. In order for her asthma-body to remain 'absent' (Leder, 1990), Tasneem made the decision to "*stop*" and "*take a break*" mid- performance. When her asthma-body interrupted her progress, Tasneem sought to minimise the disruption by using her reliever inhaler, as recommended by the BTS guidelines (2016) (see section 1.8). Unlike other participants, including Jamal, Reena, Indiana and Enayah, the use of the reliever inhaler did not seem to be a 'marker' of an unsuccessful, or undesired (Goffman, 1959) sporting performance of self for Tasneem. Instead, Tasneem utilised breathing techniques to move away from a 'dys-functional' body (Leder, 1990), characteristic of breathlessness, to an 'absent' or 'dis- appearing' bodily state of awareness (Leder, 1990).

According to Goffman (1959), the individuals themselves are not the only ones who help maintain the performance of self. Goffman (1959) argued that the audience can play a part and can help save other people's definition of the situation when they engage in 'protective' practices. The 'definition of the situation' (Goffman, 1959) (see section 3.2) is about how people construct the meaning of a situation based on their experiences and try and persuade others of his/her definition of the situation. Protective practices are social actions used when the audience seeks to protect the performance of others (Goffman, 1959). For Samina and Reena, having the help of their exercise instructor enabled them to protect their performance of sporting-self:

> *"…my [Zumba] instructor is a severe asthmatic, so she tells me: 'make sure you do this, make sure you do that', just to ease it off a little bit"* [Samina, Interview 1]

> *"…she'll tell me when to take my inhaler and what to do if I feel short of breath…but she's asthmatic as well, so she takes 30 second breaks to take her inhaler and just calm down a bit as well"* [Samina, Interview 1]

Samina explained that her Zumba instructor had severe asthma and guided her through the exercise class. The guidance from her instructor helped Samina to find the right balance. Applying Goffman's (1959) insights would indicate that Samina's instructor engaged in a protective practice when she saw Samina becoming breathless, thus saving Samina's performance of sporting-self by telling her to take her inhaler. Additionally, it is possible that Samina's instructor improved Samina's confidence to use the reliever inhaler mid-performance when she used her own reliever inhaler and took 30 second breaks during the class. Consequently, using the reliever inhaler mid-performance might not be characterised as 'losing face' (Goffman, 1959) for Samina if her instructor used her reliever inhaler mid-performance also. Similarly, to Samina, Reena discussed how her exercise instructor monitored Reena's asthma-body during circuit training[18]:

> *"She's [exercise instructor] the one who turns it down for me when I'm in circuits. She can tell I can't cope; she can tell if my breathings a bit heavy; or if my breathings a bit laboured. She can tell if my breathings starting to kick off, so she tones it down for me"* [Reena, Interview 2]

Comparable to Samina's instructor, Reena's instructor engaged in a 'protective practice' (Goffman, 1959) when she 'toned' it down for Reena. This was because Reena's instructor recognised when Reena's body shifted from a 'dis-appearing' bodily state to a 'dys-appearing' mode (Leder, 1990), even when Reena herself was seemingly not aware of this bodily shift. Reena was particularly appreciative of her instructor's ability to "*tone*" down and "*improvise*" the exercise routine for her, in order for Reena to save her definition of the situation, as well as her sporting performance of self: *"I like the fact that she knows my body and she knows me quite well and she's willing to improvise for me"* [Reena, Interview 2]. According to Leary (1992), people tend to try harder and exercise harder when others are observing their

[18] Circuit training involves high-intensity aerobics and is a form of body conditioning (Avallone & McLeish, 2013).

behaviour, believing that doing so will create a desired impression. Thus, their sporting and/or exercising behaviour has self-presentational implications. The danger, however, is that some people may exert themselves too much and create health risks, such as, exhaustion. In the current research, Reena carried on exercising during her circuit training, even though she was experiencing symptoms. Leary (1992) argued that sporting people may conceal or deny their exhaustion, in order to show that they are 'fit' and 'healthy'.

5.6.1.1 Summary

In this subordinate theme, Maryam, Enayah, Indiana, Reena, Jamal, Kalan, Priti, Samina, Lubna and Tasneem created their 'idealised' (Goffman, 1959) sporting performances of self by using different approaches to find the right balance. Maryam, Enayah, Indiana, Reena and Priti experimented with various exercises and sports in order to find which types of activities best suited them. This enabled them to either remain in a 'dis-appearing' (Leder, 1990) bodily state of awareness, or achieve 'eu- statis' (Zeiler, 2010). For Jamal, Reena, Indiana and Enayah, their 'idealised' (Goffman, 1959) sporting performance involved trying to distance themselves from using the inhaler mid- performance. This was because the use of the reliever inhaler mid-performance was characteristic of an 'unsuccessful, or 'undesired' performance of sporting-self. Additionally, the use of the inhaler mid-performance interrupted sporting progress for some participants. Kalan and Samina, on the other hand, used their reliever inhalers as a form of pre-dosing to ensure that they could present their desired impression of sporting-self. This minimised disruption and is analogous to the BTS (2016) guidelines, which recommend using the reliever inhaler 15 minutes before participation to reduce the risk of symptoms. Further, Reena and Samina, were offered guidance to find the right
balance during exercise. Their instructors helped them 'save face' by engaging in protective practices (Goffman, 1959) either by monitoring sporting progress or offering advice about when to use the reliever inhaler mid-performance. The following subordinate theme titled, 'Feeling self-conscious', explores some of the techniques the participants described to manage the presentation of their sporting self, when they performed in front of other people.

5.6.2 Feeling self-conscious

As discussed in the previous subordinate theme (section 5.6.1), managing sport and exercise involved finding the right balance. When the right balance was achieved, it helped the participant present an 'idealised' (Goffman, 1959) performance of the sporting-self; one that

involved remaining in a 'dis-appearing' (Leder, 1990), or 'eu-static' bodily state of awareness. In this subordinate theme, participants' accounts showed that when they entered a 'dys-appearing' state (Leder, 1990) and began to experience symptoms, they felt self-conscious about their performance of asthma, sporting-self.

Goffman (1959) argued that people use impression management skills to prevent disruption to social interaction. If a person is unsuccessful at achieving a successful interactional performance, that is, one which has not been disrupted, he/she can get embarrassed (Goffman, 1959). Reena's, Nafisa's, Jamal's, Priti's, Maryam's and Enayah's transcripts indicated that they often felt self-conscious when their asthma-body-self was revealed to others, particularly within a sporting environment. The participants used strategies to try and control their sporting performance of self and to conceal their asthma-body-self. When they masked their asthma-body-self, their performance of sporting-self was unaffected. On other hand, when their asthma-self was revealed, or when symptoms were displayed to others, it equalled an undesired performance. When this happened, the participants felt embarrassed. Embarrassment is defined as an unpleasant feeling of awkwardness, which happens when a person believes they have relinquished control of a situation in front of an audience (Goffman, 1959). This subordinate theme investigated this in line with Goffman's (1959) self-presentational analysis and discussed how some participants attempted to control their sporting performance in front of other sporting peers and bystanders.

Reena stated that she would feel uncomfortable if her symptoms were revealed to others, or more specifically, if her symptoms were exposed to her sporting peers in the gym:

> *"…I do the fit training at <u>home</u> because sometimes my chest gets really tight. I don't want to be in in the gym, puffing away my inhalers every second. I wouldn't feel comfortable"* [Reena, Interview 1]

> *"…so, I avoid doing that sort of training [fit training] in the gym… but I don't mind doing the weights… walking casually on the treadmill but if it's anything intense I tend to do it at home, so I'm not interrupted by asthma…"* [Reena, Interview 1]

Reena's accounts indicated that she was conscious about her sporting performance of self when she was at the gym. Reena's audience were her sporting peers. She was aware that "*anything intense*" might lead to a 'dys-functional' bodily state (Leder, 1990). If this occurred, her

performance as a 'normal' gym goer, could be disrupted and could lead to an undesired and discredited body-self (Goffman, 1963) to her sporting peers at the gym. The depiction of her "*puffing away*" on her inhalers "*every second*" suggested that the inhaler was a discrediting feature (Goffman, 1963) of asthma. In Goffman's (1963) terms, discrediting attributes are those which do not meet societal standards of 'normal' behaviour. Using the inhaler in the gym acted a 'marker' of asthma and could have potentially marked participants negatively as 'different' from 'unmarked' others (Allen-Collinson, 2009), even if they did not feel different. In an attempt to avoid being discredited by her sporting peers in the gym, Reena avoided doing "*intense*" activities, including fit training in the gym. Instead, she undertook these activities in her home and in an area unseen by other gym goers. According to Goffman's (1959, pp. 112-113) insights, people can present different performances in environments which may be unobserved by others; these environments are called the 'back stage or the back regions of life' (see section 3.3). In Reena's case, her home acted as this unseen environment, where it was presumed she was less conscious about her sporting performance of self. In her follow up interview, Reena felt particularly self-conscious about "*struggling*" in front of others at the gym: "*I wouldn't feel comfortable if I started struggling in the gym. I just wouldn't feel comfortable…"* [Reena, Interview 2]. Visible displays of pain, or in this case, symptoms of asthma were to be avoided from Goffman's (1963) perspective because it would increase the risk of stigmatisation and demonstrate to others that the person with asthma does not have a 'fit and healthy body', commensurate with a sporting identity (cf. Goffman, 1963; Leary, 2019). According to Leary (2019), people can experience social anxiety when they want to present a desired impression to others, but question whether they will be successful in doing so. Although there are studies in the area of social anxiety and interpersonal interactions, for example, speaking in public, Leary (2019) argued that sporting individuals can experience social anxiety when they become concerned about their audience's impressions.

In the current research, it was clear that Reena preferred not to present a "*struggling*" body-self to her sporting peers at the gym and was anxious about portraying such a self to others. Struggling could be deemed an undesirable trait in a sporting environment, where there is a strong association between sporting activity and physical fitness. According to Leary (1992), sporting individuals can be concerned about how others will view them during participation. This may lead them to not exercise at all, or exercise alone (Leary, 1992). In the current research, this was the case for Reena, who exercised at home in fear of becoming embarrassed.

Nafisa expressed a similar view about displaying her asthma-body to others:

> *"…running. It wouldn't be great to be going [imitates breathlessness by breathing in and out quickly]. People look at you, don't they?"* [Nafisa, Interview 2]

She explained that breathlessness during a run indicated a loss of control, which subsequently generated attention from bystanders. A breathless sporting-self, much like a struggling self, can be perceived as discreditable features of Nafisa and Reena's sporting performance of self. Nafisa elaborated on this issue:

> *"…I don't wanna be sort of standing having an asthma attack and attracting attention and people worrying. I know I don't need to go to the hospital, but people stopping and saying: 'oh, you okay?'…"* [Nafisa, Interview 2]

Bodily 'dys-function' (Leder, 1990) during sport generated unwanted attention in Nafisa's case. According to Goffman (1963), situations which are not usually considered to be part of the 'normal' social order can produce the unpleasant feeling of awkwardness (Goffman, 1963). Nafisa's account suggested that "*having an asthma attack*" might interrupt the 'normal' social order, which seemed to make bystanders stop to question her. Her 'planned' sporting performance then, one where her symptoms remained in control and concealed from others, was disturbed by both her symptoms and the attention from others. Previous evidence has shown that sporting individuals engage in health-damaging behaviours, such as, failing to seek medical attention because this creates a negative image to others (Martin-Ginis & Leary, 2004). Although Nafisa did not seek medical attention, she described how she became more "*mindful*" to use her inhaler to prevent oncoming symptoms:

> *"…when I was exercising, I was mindful to use the pump every day because of the fact I had to literally stop in the middle of the road, and if anyone was passing in that moment, they would know that I was struggling to breathe because it was visibl[e], could not breathe properly"* [Nafisa, Interview 1]

Nafisa explained that she was *"mindful to use the pump everyday",* demonstrating that the inhaler, or "*pump*" was part of her impression management skills and used as part of a 'pre-established pattern' (Goffman, 1963) when she exercised. This was so that Nafisa could present the desired impression and conceal her asthma-body-self during exercise. This was particularly pertinent for Nafisa, who seemed to be self-conscious about her sporting

performance of self when she was exercising in front of others. It was unclear whether Nafisa used the reliever inhaler as a form of pre-dosing, or whether she used the inhaler mid-performance. Goffman (1959) argued that individuals are continuously trying to sustain the general social order in their interactional encounters with others. If he/she acts out, the individual can become embarrassed. Enayah explicitly stated that she experienced embarrassment when her asthma-body revealed itself to others:

> *"The wheezing starts like there's no tomorrow. The whole room will know that 'uh oh, here she goes', can be quite embarrassing at times cos you don't want anyone to look at you cos you're having this problem breathing. They're all like: 'you ok, are you ok?', [Enayah replies] 'yeah I'm fine, please just don't look at me'"* [Enayah, Interview 1]

Like Nafisa, Enayah concentrated on how her performance of asthma-self was being viewed by others. After unintentionally revealing a 'wheezing self' to others, Enayah's attention was drawn to the "*whole room*" and like Nafisa, she preferred not to have anyone look at her or question her. For Nafisa and Enayah, questioning them about their 'dys-appearing' (Leder, 1990) bodily state seemed to add to the embarrassment or discomfort. Nafisa and Enayah's accounts suggested that they dismissed other people's concerns about their bodily state because they wanted to detract attention away from, what they perceived to be a discrediting performance of their self. Both accounts also indicated that Nafisa and Enayah had some sense of control of their symptoms and thus, may have been reluctant to accept help. This, however, could have created further problems for Nafisa and Enayah, who might have needed treatment. Seeking help could be difficult for participants who are worried about being embarrassed or stigmatised by their asthma-self. Maryam and Jamal explained how the inhaler can be viewed as stigmatising:

> *"…sometimes <u>can</u> be embarrassing <u>in front</u> of other people. You feel like you [have to] take your inhalers and you can't take it. In that kind of situation, can be <u>bad</u>…"* [Maryam, Interview 1]

Maryam explained that it was embarrassing when she had to take her inhalers in front of others. When she did this, she could no longer 'pass as normal' (Goffman, 1963). This was because her asthma-self was revealed to others when it was previously hidden. She insisted that it was difficult disclosing her asthma-self to others. In Maryam's account, the inhaler was perceived as a stigmatising feature of her performance as a 'normal' social actor when she

was *"in front of other people".* She noted that she could not take her inhaler in front of her audience, which subsequently made the situation "*bad*", perhaps because this would further discredit her performance of self. It seemed that if the inhaler adds to an unsuccessful performance of sporting self, people with asthma may be reluctant to seek treatment or use their inhaler in front of others. Jamal elaborated on this issue:

> *"…if I'm wheezy right now and I'm <u>really</u> struggling to breathe, I'll take two puffs of it, [reliever inhaler], so I'll breathe it in, I'll take a puff breathe it in hold for ten seconds, <u>which</u> <u>looks a bit silly</u>, cos when I'm there with my friends I'll <u>do</u> it, <u>sometimes they won't even see</u> <u>me do it,</u> cos they'll talk to me and I'm like [Jamal holds his breath in] and they're like [Jamal makes a confused facial expression] and I'm like [Jamal holds his breath and breathes out after two seconds] and then I'm like: 'sorry it's just my inhaler'. It's a bit of hassle"* [Jamal, Interview 1]

In the above account, Jamal described his inhaler technique[19]. Although he did not explicitly mention that he experienced embarrassment when he used his inhaler, his account suggested that he was self-conscious about taking it in front of his friends. He hinted that he occasionally used it quickly, which helped to conceal his actions. However, his actions were revealed when he kept hold of his breath; something which puzzled his friends. Taking the inhaler then, might look 'out of character' and thus be perceived as a "*hassle*" for people with asthma, as described by Jamal. It is important to note that Jamal referred to his friends as his audience in this example and the way he perceived this situation may be different in other contexts. For example, Jamal might not feel that his inhaler is a discrediting feature of his asthma-self when his friends are not present. In the same way, Maryam may hold different views about her inhaler in different contexts. Commensurate with the SI approach and Goffman's (1969) conceptual insights, it would be argued that the situation is defined differently by different social actors. Jamal explained that he kept his inhaler on him "*at all times*" to prevent what he perceived as "*unnecessary drama*":

> *"…I don't wanna have to be at my friend's house and call an ambulance to <u>get</u> on a*

[19] Inhaler technique (without the use of a spacer): 1. Remove cap, and shake inhaler to ensure a consistent delivery; 2. Breathe out fully; 3. Breathe in slowly and steadily, then press down on the inhaler; 4. During inhalation, hold breath for 10 seconds; 5. Breathe out slowly, and repeat process (if applicable), then replace the mouthpiece cover (Murphy, 2012).

nebuliser, or get an Uber to A&E because it is just unnecessary drama, I don't wanna have to do that in front of my friends as well, it's just a hassle, and it's just something I don't wanna be getting involved in, it just makes so much more sense to have my inhaler on me at all times" [Jamal, Interview 1]

When Jamal was with his friends, he was increasingly concerned about the presentation of his asthma-self. In order to maintain control of the situation and avoid disrupting the general social order with his friends, Jamal kept his inhaler on his person "*at all times*" to prevent presenting his symptoms *"in front of his friends".* He labelled this a "*hassle*" and something that he did not "*wanna be getting involved in*". Jamal also expressed a feeling of guilt when he experienced symptoms in front of others after experiencing an asthma attack at a charity event, where walking out of an ambulance created further attention:

"…when I was getting dropped off in the ambulance, I was just so embarrassed cos everyone was like 'why the hell is there an ambulance coming?'. It literally drove into the middle of the event; I'm then getting out and people are like 'what the hell is Jamal doing getting out of an ambulance?'" [Jamal, Interview 1]

The arrival of the ambulance served to disclose his asthma-self and discredited his performance as a 'normal' social actor, which made Jamal feel "*so embarrassed*". He later discussed how this disrupted the 'normal' social order as everyone was more focused on him than on the event itself:

"…everyone was putting an extra eye on me and I felt bad cos there's an event here, they were raising money for people a lot less fortunate than me, and they're all now having to keep an extra eye out on me which means they can't put full effort into making sure the event runs as smoothly as possible. It's just a bit unfortunate that that my asthma often hinders other people's stuff" [Jamal, Interview 1]

The context, time and place are important here. For Jamal, having attention directed towards him during a charity event for "*people a lot less fortunate than him*" might have influenced his guilt. He described feeling "*bad*" because his audience could not focus on the event. Instead, the audience became watchful of him, keeping an "*extra eye out*". Jamal suggested that his condition affected those around him. Although Goffman's (1959) self-presentation analysis argued that people feel embarrassed when social interaction is disrupted, Jamal's extract

proposed that people with asthma can feel guilty for their actions. This adds new insight to Goffman's (1959) analysis, indicating that it is not only embarrassment that people fear, but guilt for their actions. Priti also provided an example of this: *"I don't want people to worry when I'm dealing with an asthma attack, so I don't show it that much"* [Priti, Interview 2]. When she had to "*deal*" with an asthma attack, Priti tried to conceal her asthma-body-self. This was so that she could prevent her audience from worrying about her, as well as to maintain the general social order without undue disruption. A belief that asthma is something private led Priti to minimise her experience because of the guilt she felt about being the focus of attention. By not revealing much during her asthma attack, Priti attempted to 'pass as normal' (Goffman, 1959), in order to diminish her feelings of guilt.

Some participants used their inhalers to 'pass as normal'. Jamal indicated that the use of his preventer inhaler benefitted his sporting performance of self:

> *"I'll take the purple inhaler [preventer inhaler] and I'll just go about my day. You notice that you just don't need your blue one as much, so I'll notice that; 'wait, I've done this, I'm not wheezy, had I not been taking this regularly, I would actually be wheezy and I would need to use my blue [reliever] inhaler…"* [Jamal, Interview 1]

> *"…then I'll find with the purple [inhaler], if I'm taking it, I'll all of a sudden just be fine, and I can go with my friends and go to the gym and strain myself and feel more or less fine"* [Jamal, Interview 1]

In this extract, Jamal discussed how his preventative medication enabled him to "*strain himself*" when he was with his friends at the gym, allowing him to feel "*more or less fine*", suggestive of Leder's (1990) notion of the 'absent' body. When Jamal felt "*more or less fine*", his asthma-body remained in the corporeal background. As per the BTS (2016) guidelines, Jamal used his preventer inhaler regularly. In doing so, he was able to conceal his asthma-self to his friends. Relating back to the previous subordinate theme (see section 5.6.1; 'Finding the right balance'), the regular use of his preventer inhaler allowed Jamal to enact an 'idealised' sporting performance of self, when he discovered that he did not need to use his reliever inhaler mid-performance. In essence, Jamal's preventer inhaler minimised disruption from his asthma-body-self, keeping his body in a 'dis- appearing' bodily state of awareness (Leder, 1990).

According to Goffman (1963), maintaining control of the body is important for the presentation of self; individuals are concerned with the ability to be perceived and accepted as a competent

social actor by others. According to Goffman (1963), the effective maintenance and control of the body and self require a particular level of ability and competency. Goffman (1963) argued that people engage in the intentional use of tactics to manipulate the impressions others may form about them. In Jamal's case, it could be construed that the regular use of the inhaler is an intentional tactic used to control his performance of the sporting-self. For Reena, Indiana and Enayah, this related to the ways they attempted to manage their asthma-body during sport and/or exercise to avoid displaying their physical discomfort to others. Comparable to Nafisa, Jamal's daily use of his preventer inhaler suggests that it is a technique employed to help achieve his 'idealised' performance (Goffman, 1959), that is, one which included not displaying his asthma-body-self to others and one which did not require the use of his reliever inhaler mid-performance. It may be that Jamal's use of his preventer inhaler is used as part of his impression management skills, as the regular use of the inhaler helped to conceal his asthma-self in front of his audience (in this case, his friends). The extracts from Jamal and Nafisa suggested that they may be able to conceal their asthma identity and 'pass as normal' (Goffman, 1959) or as people who can participate in sport and/or exercise undisrupted.

5.6.2.1 Summary

To summarise, this subordinate theme has revealed that during times of bodily 'dys-appearance' (Leder, 1990), that is, when symptoms of asthma appear in front of others, Reena, Nafisa, Enayah, Jamal, Maryam and Priti focused on how their asthma-self was being viewed by others. They often felt self-conscious about their performance of asthma-self and preferred not to present a struggling self that was characterised by a 'dys-functional' body (Leder, 1990). If the 'dys-appearing' body (Leder, 1990) emerged during sport and/or exercise or at any other time in front of an audience, they experienced embarrassment, fitting with Goffman's (1959) theoretical insights on the presentation of self. This not only created embarrassment, it created a feeling of guilt, as in Priti's and Jamal's case. Additionally, participants used different strategies to try and conceal their asthma-self. This involved using the inhaler mid-performance (in this case, for Maryam and Jamal), although this can be stigmatising and can be perceived as a discrediting (Goffman, 1963) feature of the participants' identity. So, although the inhaler can act as a useful device to conceal their symptoms from others, it can also be a stigmatising feature of their performance of asthma-self. The figure below (see Figure 8, p. 245, overleaf) provides a conceptual model of the asthma, sporting-self.

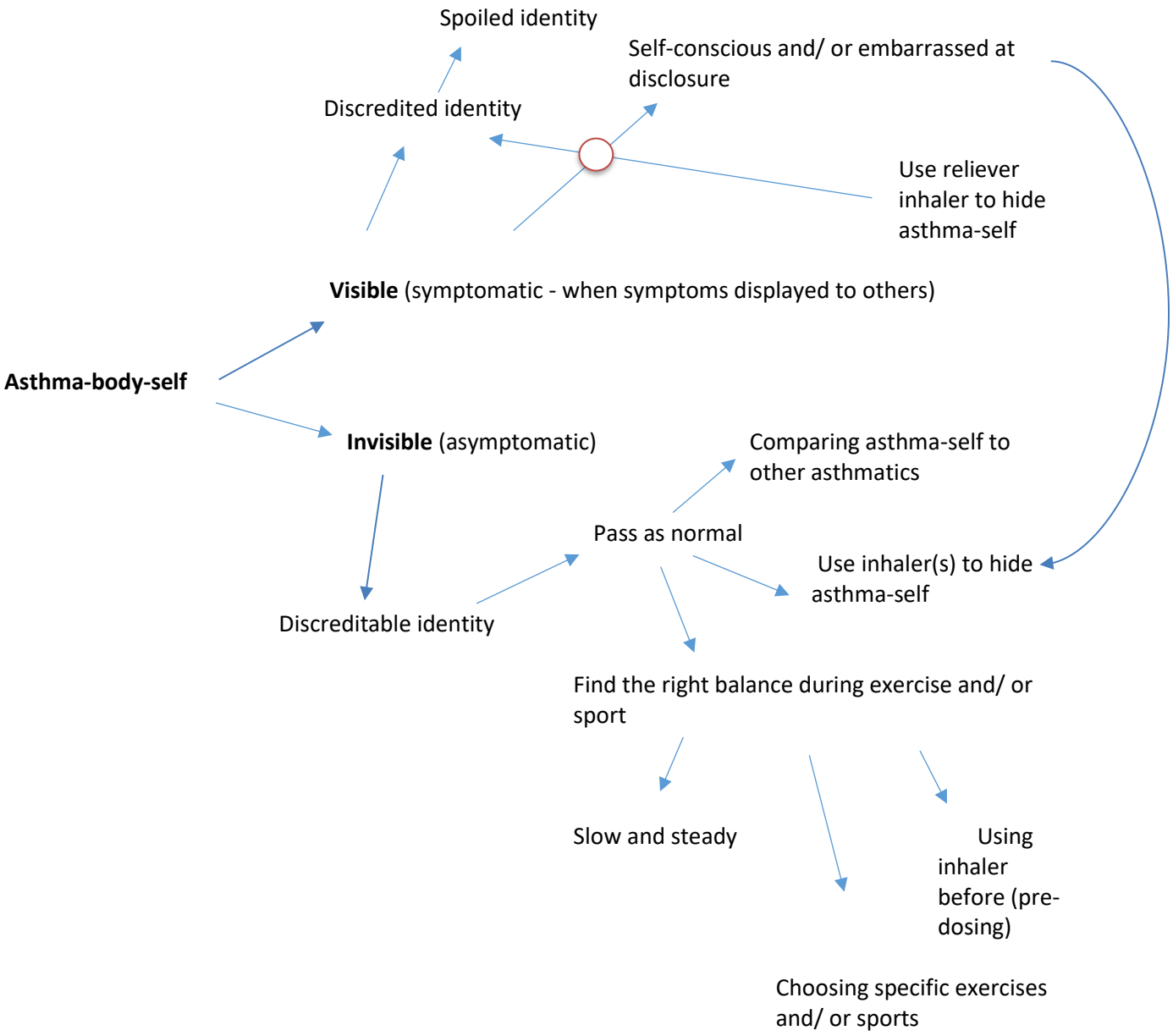

Figure 8. Conceptual model of presentation of asthma, sporting-self.

Together with the previous subordinate theme (see section 5.6.1; 'Finding the right balance'), the evidence has demonstrated that the participants manage their asthma by choosing specific exercises and/or sport; pre-dose with their inhalers; and monitor their symptoms during participation, so as not to disrupt the flow of their sporting performance. There were two main purposes for this. The first relates to physiological reasons, where getting into asthmatic difficulties and having to use the reliever inhaler to 'recover' their breathing was detrimental to the participants' level of performance in a sporting-physiological sense. The participants aimed to remain in a 'dis-appearing' bodily state of awareness (Leder, 1990), where they were

asymptomatic. The second is about interactional self- management reasons, aligning neatly with Goffman's (1959) self-presentational insights. For example, participants were wary about their sporting performance, as well as how their asthma-self was being presented to others. Therefore, getting into asthmatic difficulties and visibly having to use their reliever inhaler could be detrimental to their presentation of self as a 'normal' sport and/or exercise participant, discrediting the 'normal' identity and increasing the risk of stigmatisation. This was when they were not able to 'pass as normal' (Goffman, 1959). This can severely disrupt the interactional flow by causing embarrassment, or provoking anxiety in other interactants. The presentation of their asthma sporting-self is strategically planned and can be interactionally challenging once their symptoms start to appear, and is thus to be avoided from Goffman's (1959) perspective. The following superordinate theme explores some of the participants' experiences of stigmatisation, though, this was in relation to the cultural misperceptions of asthma, specific to South Asian communities.

5.7 Experiencing cultural stigma

In this superordinate theme, some of the participants described their experiences of stigma. This developed into two subordinate themes. The first subordinate theme; 'Dealing with misperceptions of asthma' (see section 5.7.1), detailed Nafisa's, Maryam's, Kalan's and Enayah's experiences and focused on the way asthma was perceived by other South Asians, and how this influenced stigmatising behaviours. The second subordinate theme, titled, 'Sport and/or exercise and the South Asian woman: Negotiating gender and cultural identities' (see section 5.7.2), was specifically related to the female participants' perspectives of sport and exercise, and how the female, sporting body was considered by others in South Asian communities. Goffman's (1959; 1963) theoretical insights on self- presentation (see section 3.3) and the management of stigma (see section 3.4) are used to analyse the participants' accounts and attempts to understand how some of the participants manage stigma.

As previously mentioned (see section 3.4), Goffman (1963) differentiated between those who are considered to be 'discreditable' and those who are 'discredited'. The 'discredited' include individuals who perceive that their stigmatising attribute is apparent to others in their social interactions (Goffman, 1963). The 'discreditable' include those who perceive that their stigmatising feature is not immediately visible to others (Goffman, 1963). For 'discreditable' individuals, their stigmatising feature(s) can be revealed intentionally, or unintentionally

(Goffman, 1963), as seen in the previous section (see section 5.6.2). The 'discreditable' can have some degree of control over how their stigmatising attribute(s) may be revealed to their audience(s) (Goffman, 1963). According to Goffman (1963), the 'discreditable' (in this case, those with asthma) are able to conceal their stigmatising attribute (in this case, asthma), by engaging in 'passing'. In this way, the 'discreditable' person is focused on managing his/her identity by either revealing or concealing information related to the stigmatising feature (Goffman, 1963) (in this case, asthma).

5.7.1 Dealing with misperceptions about asthma

In this subordinate theme, Maryam, who was born in Bangladesh, and Nafisa, who was born in the UK, discussed their experiences of asthma-related stigma. These accounts were often spoken with frustration and anger, as they tried to present themselves to others as South Asian people with asthma.

According to Maryam, asthma was not perceived positively in her Bangladeshi culture:

> *"…in our culture, Asian culture asthma, they don't really take it really good way. People say: 'oh you have asthma'. They [other South Asians] think it's really bad"* [Maryam, Interview 1]

Maryam's account suggested that having asthma was a discreditable feature of her identity as a Bangladeshi South Asian person and for those who identify as "*Asian*". To have asthma is stigmatising because "*they [other South Asians] think it's really bad*". Maryam spoke in frustration and in a negative voice intonation to show that having asthma was stigmatising. Using Goffman's (1963) analysis would indicate that having asthma might have made Maryam feel 'undesirable' (Goffman, 1959). The stigma attached to having asthma forced her to conceal her condition when she was younger and to protect herself from further possible discriminatory behaviours from others; *"before, I used to feel I have something really bad and I shouldn't share with other people"* [Maryam, Interview 1]. When she was younger, Maryam believed what was being said about asthma and started to "*feel*" that she had something "*really bad*". Later in the interview, Maryam discussed how several of her family members who immigrated from Bangladesh, have been diagnosed with asthma but continue to believe that it is a 'discreditable' feature (Goffman, 1959) of their identity:

"my uncle, his wife, his son, daughter, they all have asthma, so the family, they all have asthma, but they take it as really bad way" [Maryam, Interview 1].

According to Goffman (1959), managing information about a non-visible stigma (in this case, asthma) involves trying to avoid or limit stigmatisation in social interactions. Since asthma is not visible all of the time, it is considered 'discreditable' (Goffman, 1963). As long as symptoms do not spontaneously occur, asthma is not noticeable. This means that people with asthma can control or manage the presentation of their asthma-self to others (as seen in section 5.6.2; 'Feeling self-conscious'). Since Maryam's family perceived asthma to be a stigmatising feature of her identity, Maryam began to conceal the act of "*taking*" her inhalers in front of them. This was so that she could control and direct information about her condition in the sense of 'stigma management' (Goffman, 1963):

"At that time [when Maryam was younger], I used to get really upset sometimes taking inhalers and my uncles, they used to come to my house, and I didn't used to take inhalers in front of them" [Maryam, Interview 1]

Maryam's account indicated that the use of her inhalers contributed to further stigmatising behaviours from her family. As previously mentioned (see section 5.6.2; 'Feeling self-conscious'), the use of her inhaler acted as a stigmatising 'marker' of her asthma, making her feel "*really upset*". Applying Goffman's (1963) theoretical insights would suggest that the representation of inhalers in front of an audience can be stigmatising, though it depends who the audience is. In Maryam's case, her family members deemed asthma to be stigmatising, and thus, the use of inhalers was also deemed stigmatising. There is evidence demonstrating that the use of asthma medication is concealed, although this relates mostly to adolescent or childhood populations with asthma (see Lakhanpaul et al., 2014). Using Goffman's (1963) conceptual analysis would indicate that people with asthma conceal their use of medication in an attempt to control how they self-present to their audience(s). Additionally, Goffman's (1963) theoretical considerations would suggest that the act of concealing the use of medication (in this case, asthma inhalers), helps to minimise the effects of stigma and enables them to 'pass' (Goffman, 1963) as someone without asthma. Other medications for other conditions are less obvious, as they are not taken immediately to manage symptoms in the way that inhalers are for asthma. It seems that there is a choice to make about whether to take treatment or not with asthma. This decision can depend on whether the person will be

stigmatised for taking treatment. Maryam was told to conceal her diagnosis of asthma from her family by her mother:

> *"…my mum said: 'don't tell any anybody about that you got asthma', so then, I used to think: 'oh my God, this is really bad, that's why she's saying not to share', so I didn't used to tell my uncle that I got asthma"* [Maryam, Interview 1]

This instantly led Maryam to believe that asthma was something considered to be "*really bad*". By intentionally concealing her asthma identity from her uncle, Maryam tried to 'mask' or hide her asthma-self. Goffman (1959, p. 57) used metaphors such as the 'mask' to depict a form of deception in social interaction. In Maryam's case, she withheld information about her asthma-self to her uncle. Maryam explained that she kept her asthma-self 'masked' (Goffman, 1963) from other family members, including her aunt, because she was afraid of how they would react if they discovered her asthma identity:

> *"…when she [Maryam's aunt] comes to talk to my mum and then she says negative things which isn't good, so then I feel like 'oh my God, if she knew stuff about my asthma, what's she gonna think and say to other people', and that intimidates… [tuts]"* [Maryam, Interview 1]

The "*negative*" assumptions about asthma worried Maryam. Maryam was anxious about what her aunt may have thought about her asthma identity if it was to be revealed. This "*intimidates*" Maryam. She suggested that her aunt might not have understood asthma:

> *"I know what asthma is but maybe she doesn't know, and she talks bad about them, [people with asthma]. That kind of thing makes me not to share with anybody"* [Maryam, Interview 1]

Some evidence has shown that South Asians with a low education level about asthma were less likely to understand the condition (see Lal et al., 1995; Shivbalan et al., 2005; Smeeton et al., 2007). In Lal et al.'s (1995) study, for example, a general education awareness of asthma was poor in Pakistan-resident South Asian parents, which contributed to the misconceptions and social stigma of asthma. In Smeeton et al.'s (2001) study, which investigated parental perceptions of asthma in different ethnic minority groups, including UK-resident South Asian groups, it was reported that some South Asian parents were unwilling to discuss their child's asthma. For example, South Asian parents were more likely to be unhappy if their friends knew

about their child's asthma and were less likely to inform their friends about their child's condition because of the perceived stigma attached to the condition (Smeeton et al., 2007). The unwillingness to discuss their child's asthma was more likely to occur for South Asian parents who lacked post-secondary education. It was less of a concern for South Asian parents who had post-secondary education (Smeeton et al., 2007). In Smeeton et al.'s (2001) study, it was demonstrated that there may have been a connection between UK-resident South Asian parents' educational level and knowledge about asthma and the perceived stigma attached to having asthma. It was unclear, however, which specific South Asian groups Smeeton et al. (2007) were referring to for this particular result (see section 2.2.2). In the current research, Maryam spoke about the UK- resident Bangladeshi South Asian community. Maryam tried to challenge the stigmatised identity placed on her by her family by educating them about asthma:

> *"…when I get chance, I do speak to her [Maryam's aunt]. Whenever she says something's not good, for example, a disease, an illness, I try to explain to her: 'this is not what you think, this is how it works, and this is what it is'. I explain to everybody who has that bad thinking about asthma or anything else"* [Maryam, Interview 1]

Maryam explained that she was raising education awareness about asthma and other illnesses in her family. This was to dispel any incorrect or inaccurate beliefs and to eliminate "*bad thinking*" about asthma. This related to her previous accounts, where asthma was portrayed negatively by her aunt and uncle. It seemed that Maryam sought to influence how asthma was perceived by those who stigmatised her (in this case, her aunt and uncles) by educating them about asthma. In doing so, she may have tried to influence or change the negative perceptions about having asthma in the Bangladeshi South Asian community. According to Goffman (1963), it is always a relational flow of power and people are never able to unilaterally influence others. This means that Maryam can try to influence her family members' perceptions and teach them about asthma, but she cannot control what her family might believe after she has educated them. When she sought to challenge her stigmatised identity, it did not always work:

> *"…they think our child can never get asthma. They always have in their mind that only elderly people, or people when they get old, then they have asthma, even though sometimes I do take my asthma inhalers in front of them, but they don't believe, they're like: 'why you taking those?'. I'm like: 'I've got asthma'. They're like: 'no you don't have*

[asthma], stop taking them [inhalers]'. I'm like: 'ahhhh!'" [Maryam, Interview 1]

In this account, it was evident that the stigma about having asthma often remained, particularly when Maryam chose to disclose her asthma-self to her family by using her inhalers in front of them. This created an exasperated reaction from her family, who did not accept that she had asthma and questioned the use of her inhalers. Instead, asthma was perceived to be a condition that affected the elderly. According to her family, only elderly people can have 'dys-functional' bodies (Leder, 1990). Maryam was 20 years old at the time of her first interview. Therefore, the use of her inhaler in front of them served to emphasise her family's disbelief. The extract ends with Maryam's vocal anger at her family's denial of her condition. It is possible that Maryam did not exhibit any symptoms when she decided to use her inhaler in front of her family members. If she was asymptomatic, her asthma-body would have been in a 'dis-appearing' state of awareness, rather than a 'dys-functional' state (Leder, 1990). If this was the case and she was asymptomatic, her family members may have been less inclined to believe that she had asthma.

In Shivbalan et al. (2005) study (see section 2.2.2), which explored parental perceptions of asthma in India in a sample of 100 parents, it was found that some of the parents were unwilling to accept their child's diagnosis of asthma because they believed asthma was a condition that only affected adults and not children. This was, however, only reported in a very small percentage (9%) of the sample and indicated that it was not a widespread belief in Shivbalan et al.'s (2005) cohort. Further, in Lal et al.'s (1995) study, which investigated Pakistan-resident parents' beliefs about asthma, it was found that more than half of their sample failed to accept their child's diagnosis of asthma, and instead used terms such as, allergy or chronic cough, to describe their child's condition. Nafisa, a UK- born South Asian, discussed the difficulty involved in accepting an asthma diagnosis for some: *"one of my [South Asian] friends, the funny thing is she'll never admit her son has asthma"* [Nafisa, Interview 1]. Nafisa explained that her friend's denial of the asthma identity for her son, was related to the stigmatising implications from such a diagnosis:

> *"She [Nafisa's friend] didn't get her son an inhaler for the short period that he needed it and I thought: 'why would you do that?. He needs it'. He's [Nafisa's friend's son] had to have a reliever cos he has <u>bronchitis</u>, but it's a connotation of when you hear, or saying that you've got asthma means you've got this long-term condition and again, that's*

seen as weak and that's this generation, that's our generation and that's really sad" [Nafisa, Interview 2]

From Nafisa's account above, it was clear that having asthma was perceived to have connotations of weakness. This reverberated with older stereotypes of asthma in the UK, which typified people with asthma as weak, sickly, and feeble (Adams et al., 1997) (see section 3.3). Although Adams et al.'s (1997) study did not investigate South Asian groups, the study found that the respondents who denied that they had asthma were more likely to describe people with asthma as 'weak' or 'decrepit' (Adams et al., 1997, p. 8). In doing so, those who denied the asthma identity self- presented as people without asthma (Adams et al., 1997).

Similarly, to Maryam's previous accounts, Nafisa suggested that the representation of an inhaler acted as a 'marker' of asthma for her friend. In the current research, it seemed that the representation of an inhaler acted as a 'marker' because it acted to differentiate a person with asthma from a person without asthma. If Nafisa's friend was to accept the use of an asthma inhaler, it would mean that she would have to accept the asthmatic identity for her son; an identity plagued by negative stereotypes, such as, being "*weak*". Nafisa expressed her sadness at these lingering stigmatising attitudes. Nafisa explained how these negative stereotypes about asthma were impacting the South Asian population:

"…we [national asthma study] are looking for second round. It's about looking at the influence of the extended family, the core, it's ingrained in our [South Asian] communities that it's not good to have asthma it's not good to have long term illness…" [Nafisa, Interview 1]

"…and because of that [the belief that it is not good to have asthma in South Asian communities], they [the national asthma study] found that South Asian people are not compliant with medication because if you're taking medication all the time, you're ill and you have asthma and it's the admission, therefore, we've [South Asian communities] got very high A&E attendance rate because [South Asian] people are not medicating correctly" [Nafisa, Interview 1]

Nafisa's accounts indicated that having asthma was related to having a 'dys-functional' body (Leder, 1990), that is, one which was perceived to be "*ill*" and "*weak*". Nafisa also revealed that there are numerous issues within South Asian communities that need to be targeted, in order to improve medication adherence. She suggested that, to de-stigmatise (Goffman, 1961) asthma,

the focus should be shifted towards the "*extended family*". This linked to Maryam's experiences of stigmatisation, who explained that her aunt and uncles stigmatise her for having asthma. Nafisa also highlighted that the *"very high A&E attendance rate because [South Asian] people are not medicating correctly"* is related to the denial of the asthma identity. Nafisa seemed to suggest that some South Asians might be non-adherent because they do not adopt the 'asthmatic' role, engaging in an extreme form of role distancing (Goffman, 1959).

Previous evidence (see Gilthorpe et al., 1998; Griffiths et al., 2001; Netuveli et al., 2005, The Tower Hamlets Joint Strategic Needs Assessment report, 2015; Sheikh et al., 2016) (see section 1.2) has reported that UK-resident South Asian adults with asthma are more likely to be at an increased risk of asthma-related hospitalisations, due to non-adherence. Other research (e.g., Singh et al., 2002) (see section 2.2.2) has demonstrated that the use of an inhaler was stigmatising, particularly for South Asian women. There was, for example, only 7% of South Asian Indian women who accepted the use of an inhaler in Singh et al.'s (2002) study, though Singh et al. (2002)'s findings were limited to South Asian Indians, who resided in India.

The current research demonstrated that some South Asian groups have difficulty accepting asthma into their lives due to the stigma attached to the condition, as evidenced by Nafisa's friend. This subsequently has treatment implications for those who deny the asthma diagnosis. This fits with previous investigations (Lal et al., 1995; Shivbalan et al., 2005), which have illustrated that asthma was difficult to accept for people who belonged to South Asian groups, including Indian communities (Shivbalan et al., 2005) and Pakistani communities (Lal et al., 1995). Goffman's (1963) conceptual insights about stigma would indicate that a diagnosis or label of asthma might be considered a 'discreditable' feature of one's identity among those who belong to South Asian communities. This is dependent on specific South Asian groups. It was unclear whether other South Asian adult generations would perceive asthma in the same way. For Maryam, this included the UK-resident Bangladeshi community. Although it remained unclear which South Asian community Nafisa discussed, it was evident that she was referring to UK-resident South Asian groups. Also, although previous inquiries about asthma-related stigma are currently more than a decade old and involved individuals who do not live in the UK, negative stereotypes about asthma and stigmatising behaviours continue to persist in some UK-resident South Asian groups, as evidenced by Maryam's and Nafisa's accounts. In response to this, Nafisa expressed her frustration at those who continue to stigmatise asthma, including her friend: *"…so what if he [Nafisa's friend's son] does! Who cares? Well, it's the same thing with*

South Asians isn't it?, the stigma" [Nafisa, Interview 2]. In her first interview, Nafisa described how she felt after discovering that asthma continues to be viewed as something to be "*ashamed*" of, or in Goffman's (1963) terms, 'discreditable' to one's identity, more than 20 years after her diagnosis: *"I was just shocked to find out that [South Asian] people were ashamed of it still…"* [Nafisa, Interview 1]. Nafisa explained that whilst asthma was perceived as a 'discreditable' attribute of one's identity in her South Asian community, her condition was less stigmatised when she attended a White majority secondary school:

> *"…when I went to secondary school, there were people with inhalers. I went to predominantly a White school, so there were probably 20 Asians out of 1200, so there were people with inhalers, and it was just an everyday normal thing, and it wasn't an issue"* [Nafisa, Interview 1]

Nafisa made a comparison to suggest that the use of an inhaler was perceived differently between "*Asian*" communities and "*White*" groups. According to Nafisa, whilst in a White majority setting, the inhaler was normalised. For Nafisa, having an inhaler in secondary school "*wasn't an issue*". She described some common misunderstandings about asthma that some South Asians have, which she believed contributed to the stigma:

> *"…and people still think that if you have asthma: 'oh, you don't tell anyone because you won't get married later on', why wouldn't anyone marry you?. I've got three children and not one of them has got asthma yet, so there's living proof that somebody with asthma may not pass it on"* [Nafisa, Interview 1]

According to Nafisa, some South Asians continued to believe that marriage prospects can be damaged for the person with asthma. At this particular juncture in her interview, Nafisa spoke in a much louder tone, and almost yelled, demonstrating her disdain at this assumption. Nafisa tried to 'prove' that asthma was not always passed on by referring to her own experiences. Nonetheless, Nafisa explained that marriage prospects can be dented because asthma was perceived to be hereditable. The fear that asthma might be passed onto children therefore damaged one's prospects of marriage.

This insight from Nafisa highlighted a specific socio-cultural dimension, with regard to the significance of marriage within the South Asian population and how asthma plays a role in this. Kniss and Numrich (2007) stated that marriage is considered as the keystone of South Asian

immigrant families and community life, hence, they make great efforts to find appropriate partners for their children (Ternikar, 2008). In a recent community-based, participatory study, which investigated perceptions of childhood asthma in South Asian groups, some of the parents spoke about the potential impact on marriage (Lakhanpaul et al., 2014) (see section 2.2.1 for a further discussion about the MIA project). Although their opinions varied, a number of respondents in Lakhanpaul et al.'s (2014) study mentioned that they would not agree to a marriage if they knew that their future son/daughter in law had asthma (p. 30). Another parent declared that they remained constantly worried about whether the groom's family would discover that their daughter had asthma, and others stated that their son or daughter would be "*disregarded*" by others (Lakhanpaul et al., 2014, p. 30). The daughter, in particular, would be "*disregarded*" because a male is supposed to look for a wife who is "*good and healthy*" and one who will not pass illness onto her children (p. 30). The evidence from the MIA project (Lakhanpaul et al., 2014) demonstrated that some South Asian people with asthma are "*disregarded*" by other South Asians because they may not be perceived as "*good and healthy*" (Lakhanpaul et al., 2014, p. 30). This reverberates with Nafisa's mention of people with asthma being viewed as "*weak*" by other South Asians in her community. Lakhanpaul et al.'s (2014) recent evidence provided an indication towards public perceptions of asthma in UK-resident South Asian communities, though Lakhanpaul et al.'s (2014) study only included parental perceptions about their child's asthma and not South Asian adults with asthma. Maryam revealed that misperceptions about asthma continue to exist, particularly when it related to the idea that asthma was contagious:

> *"These things [misperceptions about asthma], it <u>happens</u> in our [South Asian] culture, they [other South Asians] don't see as much of a good. They think that [it is a] <u>contagious</u> illness, [it] goes to other people, so I don't know. They have that thinking [laughs]"* [Maryam, Interview 1]

> *"…the people that from back home [Bangladesh], they have that kind of thinking in their mind still. I think they think that <u>asthma</u> is not really a good thing… they think they're contagious, even though they are not"* [Maryam, Interview 1]

In the first account, Maryam explained that asthma was considered to be a "*contagious illness*" and that "*it goes to other people*". In the second account, Maryam insisted that it was people who were born in Bangladesh who held the view that asthma was contagious, rather than UK-

born South Asians. There is currently no evidence to suggest that asthma is in any way, a contagious illness. Previous investigations by Lal et al. (1995) and Shivbalan et al. (2005) found that over a quarter of their samples (34.1% and 35%) believed asthma was contagious and a more recent study by Banga et al. (2017) revealed that 29.3% of India-resident mothers shared the same belief. The latter (Banga et al., 2017) illustrated that some South Asians continued to believe that asthma was a contagious illness. These studies, however, were based in India and did not investigate a UK-born and/or UK-resident sample (Lai et al., 1995; Shivbalan et al., 2005; Banga et al., 2017). In the UK, findings from the MIA project (Lakhanpaul et al., 2014) and Cane et al. (2001), both of which included UK-resident South Asians, reported that some of their respondents held the same belief about asthma, although it was unclear where the respondents were born. Therefore, it was unclear whether it was only non-UK born South Asians who held this misunderstanding about asthma. For Maryam and Nafisa, there was a sense of frustration and anger at the prevalence of stigma in South Asian communities. Lakhanpaul et al.'s (2014) findings from the MIA project have shown that education awareness about asthma is required in order to challenge any misinterpretations about the condition. However, it is discerning to suggest that stigma is prevalent in all South Asian communities.

In the current research, Maryam referred solely to the Bangladeshi-born community. Unlike previous sections (see section 5.5; "Other South Asian's are lazy"; Challenging cultural standards'), where participants described South Asians as a homogeneous population, here, Maryam explicitly stated that in terms of cultural stigma, it was only specific to the Bangladeshi-born community. It was unclear which community Nafisa discussed in her accounts, who treated the South Asian population as homogenous in this subordinate theme. Additional research needs to pinpoint exactly which South Asian groups require further education about asthma (this is discussed in more detail in section 7.2). In an attempt to find meaning, Maryam explored the reasons why others in her community chose to perceive asthma in this way. She explained that the media often exaggerated the symptoms of asthma:

> *"I think it's because of the [Bollywood] movies. They teach you, they put attacks really bad, they show attacks every two seconds and I think because of that, maybe they [other South Asians] have that perspective that asthma is [a] really bad thing"* [Maryam, Interview 1]

According to Maryam, Bollywood movies mislead people in her South Asian community to

believe that asthma was a "*really bad thing*" because they over-dramatise it. Maryam explained that dramatic portrayals often depicted someone with asthma who experienced asthma attacks incessantly. This type of exaggerated portrayal of asthma angered and upset her:

> *"…I can get angry and upset when I see those things [over-dramatised portrayals of asthma] in the movies. They portray asthma as [a] really bad thing, bad disease. It's a condition. I don't know why people portray, they make it really dramatic"* [Maryam, Interview 1]

According to Maryam, the dramatisation of asthma obscured the true nature of the illness by those who experienced it first-hand. Additionally, the depiction of asthma as a *"really bad thing, bad disease"* added to Maryam's anger. It seemed that media portrayals of asthma served to stigmatise those who had asthma. Further, Maryam's account indicated that she was frustrated at the term "*disease*". This was because she perceived asthma to be a "*condition*", rather than a "*disease*". Asthma UK (2019d) and the NHS (2018a) adopt the term 'condition' to describe asthma. According to Cordier (2014), the term 'disease' denotes the pathophysiological response of asthma, whereas the term 'condition' refers to an abnormal state of health that interferes with a person's typical activities. Therefore, the meaning attached to the term 'disease' focuses on the physical manifestations of asthma and it seemed that this was what media portrayals emphasised. This created an inaccurate and melodramatised portrayal of asthma and Maryam explained that this contributed to the stigmatising beliefs about the condition.

In complete contrast to Maryam and Nafisa, Enayah and Kalan explained that asthma-related stigma did not exist in their South Asian communities:

> *"…I think every other person, especially in the Pakistani culture, tends to always have one member of the family that has got it, so it's not something that I feel there's a kind of stigma attached to it, cos like I said, it's so common"* [Enayah, Interview 1]

> *"…with asthma, I'm not necessarily seeing that I would relate as a stigma, there's a condition that exists, but it seems to be generally accepted and that's what it is, and therefore there isn't a feeling of a sense of failure on individuals' part or the community or did we do something wrong, but that [it] is just one of those unfortunate things that*

seems to happen…" [Kalan, Interview 1]

Enayah's and Kalan's accounts indicated that the stigma related to asthma was non-existent because it was perceived to be "*so common*" and because it was "*generally accepted*" by their own South Asian communities. The latter directly contrasted with Nafisa's and Maryam's accounts and also to some of the previous research (see Lal et al., 1995; Shivbalan et al., 2005), which has shown that asthma was difficult to accept in some South Asian communities. In addition, Kalan's account demonstrated that some South Asians, in contemporary times, did not blame themselves for the causation of asthma. Kalan's and Enayah's accounts suggested that not all UK-resident South Asian communities shared the same beliefs about asthma, and thus, some South Asian groups did not stigmatise people with asthma. Enayah, for example, referred specifically to the "*Pakistani culture*", to denote that this community did not stigmatise asthma. It was unknown which South Asian community Kalan referred to, nonetheless, his account revealed that asthma was accepted as a part of his community. The current research suggested that, although stigmatising beliefs were non-existent for two participants, asthma-related stigma continued to persist for others, as recounted by Maryam and Nafisa.

5.7.1.1 Summary

In summary, this subordinate theme has revealed that Maryam experienced stigmatisation for having asthma and using her inhaler. According to Maryam's accounts, it seemed that her family members' perceived asthma as a 'discreditable' (Goffman, 1963) feature of her identity and disputed the idea that she needed an inhaler. Instead, asthma was perceived as an 'elderly' person's illness by Maryam's extended family. Due to these misperceptions about asthma, Maryam previously tried to conceal her asthma-self from her family and 'pass as normal'. She engaged in controlled acts of self- disclosure (Goffman, 1963), by concealing her diagnosis from them, and using her inhalers when they were not present. Maryam believed that asthma was stigmatised because it was not understood and also because of other influences including the media, where the portrayal of asthma was melodramatised in Bollywood movies. According to Maryam, this in turn, influenced other South Asians' perceptions towards asthma.

Additionally, the representation of the inhaler acted a 'marker' because it differentiated an asthmatic person from a non-asthmatic person. In Nafisa's accounts, it was demonstrated that asthma was linked to notions of being weak and the inhaler was rejected because of the negative connotations attached to using the inhaler. Commensurate with previous research,

having asthma was perceived as contagious (e.g., Lal et al., 1995; Shivbalan et al., 2005), though, in the current research, this was only the case for Bangladesh-born South Asians. Also, Nafisa's accounts showed that having asthma could be damaging to marriage prospects (e.g., Lakhanpaul et al., 2017). Both Maryam and Nafisa expressed their frustration that these stigmatising attitudes continue to persist in their communities. In attempts to de-stigmatise the condition in their respective communities, Maryam and Nafisa negotiated their stigmatised identities by challenging the misperceptions about asthma.

Further, this subordinate theme found that stigma was not prevalent in all South Asian communities. Instead, it seemed to be situated in specific groups. Kalan and Enayah, for example, insisted that asthma-related stigma did not exist in their communities. Since there were clear differences within communities, it is imperative that the UK South Asian population are not treated as homogenous group. Instead, the differences within communities is important, as it illustrates the importance of specifying which South Asian communities require further education about asthma and where stigma may be prevalent. The following subordinate theme continues to explore how stigma is experienced in relation to sport and exercise behaviour, and how some of the female participants negotiate their cultural and gender identities to perform as South Asian sporting women with asthma.

5.7.2 Sport and/or exercise and the South Asian woman: Negotiating gender and cultural identities

This subordinate theme developed from Dhaya's, Nafisa's and Lubna's experiences of sport and/or exercise as South Asian women with asthma, focusing specifically on their participation in outdoor sport and/or exercise. Using Goffman's (1959) self-presentational insights, in combination with SI's role theory and Zeiler's (2010) notion of the 'eu-static' body to analyse the women's accounts, this subordinate theme aimed to understand how the women presented themselves, according to their gender and cultural role expectations. First, Dhaya, Nafisa and Lubna listed some of the reasons, particularly with a gender focus, why they believed South Asian women were less likely to participate in sport and/or exercise. Nafisa and Lubna explained that, as part of some South Asian cultures, women were less encouraged to do outdoor sport. This was because South Asian women were more likely to be concerned about how they were perceived by other South Asians (see Ahmad, 2011) (see section 2.3.2), because of the way they were required to dress during sport and/or exercise. The fear of being

'discredited' and stigmatised (Goffman, 1963) for looking inappropriate played a role in the lack of sporting participation.

Kowalski and Leary (1990) argued that self-presentational concerns can influence people's decisions to engage in specific activities. People are less likely to participate in sport and/or exercise that convey impressions which contradict their role expectations and conflict with the 'normal' expected social order. According to Ahmad (2011), the idea that exercising or engaging in sport outdoors for South Asian women was something traditionally dominated by South Asian men. In the current research, some of the women had participated in, or were currently engaging in outdoor sport and/or exercise. From the SI perspective, it seemed that it was not part of women's role expectations to exercise and/or play sport outdoors. Dhaya explained that, although she attended the gym, other South Asian women and/or girls were not inclined to join her there:

> *"I think it's more the [South Asian] boys that do that [play cricket], rather than a lot of the [South Asian] girls, I don't really see a lot of my [girl] friends, actually I've got one or two [girl] friends that do join me sometimes, I think a lot of the time girls don't really actually go out, go to the gym or things like that*" [Dhaya, Interview 1]

Dhaya's account suggested that South Asian men and/or boys are more likely to play outdoor sport, namely cricket. Dhaya indicated that this was because some South Asian women, or "*ladies*", were uncomfortable about outdoor exercise and/or sport:

> *"…so, to expect that you're gonna get some of the ladies exercising [outdoors], they probably wouldn't, they don't feel comfortable with that [outdoor exercise and/or sport]"* [Dhaya, Interview 1]

Dhaya did not explain why she thought some South Asian women might feel uncomfortable exercising outdoors and it was unclear which South Asian community she was referring to in her account. It is possible that women feared that they would be stigmatised. Previous research (Ahmad, 2011; Koshoedo et al., 2015) (see section 2.3.2) has shown that South Asian women were often expected to dress, behave and act in a specific way. These cultural and gender role expectations included the maintenance of specific dress codes, such as loose-fitting clothing and having restricted access of movement outside of the home (Williams & Sultan, 1999; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Jepson et al., 2008, Ahmad, 2011) (see section 2.3.2). According to Koshoedo et al. (2015), some South Asian

women were either required to, or wanted to adhere to their cultural expectations, which subsequently influenced their decision to engage in exercise and/or sport. The desire to maintain a specific dress code was more pronounced for Muslim women, which often included wearing loose-fitting clothes (Williams & Sultan, 1999; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Jepson et al., 2008, Ahmad, 2011). Applying Goffman's (1959) conceptual insights would indicate that South Asian women were expected to use their appearance to present an appropriate female South Asian self to others during sport and/or exercise. Nafisa expanded on this and suggested that the issue lied with the way South Asian women were viewed by others: *"I think women possibly don't wanna be <u>seen</u> running [outdoors]"* [Nafisa, Interview 2]. In her account, Nafisa emphasised the role of clothing when presenting oneself to others as a South Asian sporting woman:

> *"…clothes might be an issue, I'm not sure, but again I don't care about my leggings, but I wear jogging bottoms and a hoodie or a t-shirt, I make sure I'm covered but I think it's in our culture, Asian culture*" [Nafisa, Interview 2]

According to Nafisa, cultural and gender role obligations to wear what is considered appropriate clothing might influence the decision to engage in sport and/or exercise for South Asian women. Using Goffman's (1959) insights would suggest that a South Asian woman (performer) might have to look a certain way, which is influenced by the audience (other South Asians in their communities). In SI terms, the social actor (in this case, Nafisa) exerted social agency. Her performance of her South Asian, female, sporting-self, however, was restricted by her cultural and gender role expectations to wear loose-fitting clothing. Nafisa stated that she did not care about her "*leggings*", nevertheless, she contemplated the type of clothing which would make her appear modest. Although Nafisa suggested that there might be a requirement to dress appropriately in South Asian communities, there may have also been a religious requirement to dress modestly, which influenced her decision to cover up. Nafisa self-identified as a British Muslim, with Asian heritage. The Islamic faith normally requires sporting women to cover their bodies, as a way to protect their modesty (Williams & Sultan, 1999; SportScotland, 2001; Carroll et al., 2002; Lawton et al., 2006; Netto et al., 2006; Jepson et al., 2008, Ahmad, 2011).

Goffman (1959) argued that people are concerned with their 'demeanour' and use 'sign vehicles' to present an effective presentation of self. In Nafisa's account, her use of *"jogging bottoms and a hoodie or a t-shirt",* were used as 'sign vehicles' and as a form of impression

management to demonstrate her modest appearance to others in her South Asian community. Workman and Freeburg (2010) used role theory to analyse teachers dress codes in the US, to understand which types of clothing expressed role embracement or role distance. Their study found that dressing in conventional clothing was considered appropriate dress and expressed role embracement. Casual or immodest dress, on the other hand, reflected role distance. In the current research, it seemed that Nafisa embraced her roles as a Muslim South Asian woman by covering up, though, this seemed to be influenced by her cultural and gender role expectations. The question remained as to whether she truly embraced her roles as a Muslim Asian woman, or whether she did so because of her role obligations to cover up and appear modest. She did, however, engage in role distancing (Goffman, 1963) and exerted agency when she participated in outdoor exercise; something deemed 'uncomfortable' for South Asian women, according to Dhaya. This itself was a paradox because Nafisa distanced herself from her role as a South Asian woman, yet, only did so within the confines of the cultural convention. She, therefore, exerted agency to engage in sport, but she did so within accepted norms by dressing appropriately.

Goffman (1959) noted that an individual can only construct a small part of how they are viewed by others through sign vehicles and demeanour. This is because the individual cannot control how their audience will interpret their portrait of 'self'. Although Nafisa did not explicitly state that she would be stigmatised for her state of dress, her account indicated that wearing 'inappropriate clothing' might be an issue, implying that it would increase the risk of stigmatisation for South Asian women exercising outdoors. Applying Goffman's (1963) insights on stigma would indicate that 'tight-fitting' clothing, or what might be perceived as inappropriate clothing, is discrediting to a South Asian woman's identity. Zeiler (2010) (see section 3.5.2) argued that people's perceptions were important to the appearance of the body. According to Zeiler (2010), the body could appear to the individual as 'dys-functional' because of how others looked and acted towards him/her, which would make the individual feel uncomfortable or afraid. If this happened, the person would become acutely aware of his/her body, which would then hinder the individual to act as freely as he/she did before. Goffman's (1959) insights would indicate that it is the audience who influences how the individual should behave. By combining Zeiler's (2010) phenomenologically-inspired insights and Goffman's (1959) self-presentational analysis in the current research, Nafisa's account would suggest that her South Asian female body was dressed appropriately when she wore "*jogging bottoms and a*

hoodie or t-shirt", to ensure she was covered. This helped detract attention away from her body from other South Asians (in this case, her audience). In this way, her body remained 'absent' and in the corporeal background (Leder, 1990) because the audience was not looking or acting towards her in ways which might have made her feel uncomfortable or afraid. By constructing her demeanour to follow cultural and gender role expectations, Nafisa was at less risk of stigma during sport. This warrants further investigation of how South Asian women may be required to present themselves to others (or their audience) in their own South Asian communities, and how the perceptions of others may affect how their body appears to them during sport and/or exercise. Also, it remains unclear which South Asian communities Nafisa and Dhaya are referring in their accounts, which again, merits further attention towards the complexities of sport and/or exercise behaviour within different communities in the UK-resident South Asian cohort.

Nafisa and Lubna suggested that the different ways in which men and women are socialised in their South Asian communities also played a part in South Asian women's attitudes towards sport and/ or exercise:

> *"You often don't see it [South Asian women and/or girls engaging in sport and/or exercise], particularly in South Asian cultures. I feel like girls aren't always encouraged to do intense exercise and go out of their way to exercise*" [Lubna, Interview 2]
>
> *"Our [South Asian] boys did mainly play football once a week, that's their thing, and it's encouraged, it's okay, whereas the women either get together, go for a meal, or sit at home, catch up on their chores, and that's just the way it's always been"* [Nafisa, Interview 2]

In both accounts, Nafisa and Lubna explained that there was a lack of encouragement for South Asian women to engage in sport and/or exercise. In the second account, Nafisa revealed the distinct differences in socialisation for men and women. South Asian men or "*boys*" were encouraged to participate in football, and it was consequently perceived as *"their thing*". Applying Goffman's (1959) insights would suggest that it was appropriate for South Asian men to adopt a sporting role because, as Nafisa stated, it was "*their thing*"; it was part of the expected social order for South Asian men and/or boys to play football. In complete contrast, South Asian women were expected to become involved in non-sporting activities. It seemed that South Asian women were expected to engage in specific culturally-valued and gender role expectations; a role which did not include 'doing intense exercise', or 'playing football'. Nafisa

clarified that these types of attitudes towards sport and/or exercise have been permeated or internalised in her South Asian culture. This subsequently defined the way South Asian women behave. By engaging in sport and/or exercise, Nafisa and Lubna engaged in an act of role distancing (as previously mentioned in section 5.5; "Other South Asians are lazy": Challenging cultural standards') and have actively re-created a South Asian sporting woman's role performance in the modern landscape.

According to Giulianotti (2004), early attempts to understand the low rates of female sport participation related to the concept of 'role conflict'. The role of athlete, for example, was inconsistent with the stereotypical role of 'femininity', which therefore meant role conflict. These stereotypical notions and role expectations of being a 'woman' kept women from engaging in sport. Giulianotti (2004) argued that Goffman's (1959) dramaturgical analysis seemed to have re-conceptualised role-taking, with an approach that proposed identities are created and re-created in interactions. The concept of 'role distance' (Goffman, 1959), for example, has emphasised a sense of agency for women, who could adopt role distancing, in order to engage in sport and/or exercise and solve the conflict between differing role expectations. Some evidence has suggested that gender-related attitudes and behaviours towards sport and/or exercise in UK-resident South Asian communities were beginning to change (see Andersson, 2002; Ahmad, 2011) (see section 2.3.2). The majority of work (e.g., Fischbacher, Hunt & Alexander, 2004; Sriskantharajah & Kai, 2007; Williams et al., 2009; Babakus & Thompson, 2012; Greenhalgh et al., 2015) (see section 2.3.2) has however, continued to demonstrate that South Asian women remained inactive for several reasons and were expected to subscribe to 'traditional' values of womanhood, including completing domestic chores and taking care of the family. In some studies (SportScotland, 2001; Lawton et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008), emphasis was placed on women to prioritise familial obligations, instead of their independence to engage in sport and/or exercise, and for them to attend to domestic chores. This resulted in less leisure time to spend doing sports and/or exercise (Misra, Endemadd & Ayer, 2005). This did not necessarily mean that Nafisa performed her 'South Asian' gender and cultural role expectations. Instead, Nafisa explained that she was atypical of a "*very cultural life*":

> *"I think it's [sport and/ or exercise] important and I don't see why everyone shouldn't [take part in sport and/ or exercise]. I don't see why it should be an issue, but then that's detaching yourself from the South Asian side, but also, I've seen quite a few South*

> *Asians in our generation who are actually running more now and they're doing the couch to 5k which helps you to run. I do know that people are getting more active. When I did the [marathon] run, my mum encouraged me and it wasn't seen as a negative thing"* [Nafisa, Interview 1]

Using Goffman's (1959) concept of role distancing, Nafisa's account indicated that she distanced herself from what she called, the "*South Asian side*", when she engaged in sport. Nafisa was explicit about detaching herself from the *"South Asian side*", which presumably related to her previous account of living a lifestyle unattached from family (see section 5.5; "Other South Asians are lazy": Challenging cultural standards). Instead, she explained that her mother encouraged her to take part in running and that she saw others who were "*getting more active*". Nafisa went on to mention in a cynical tone that other South Asians were bemused that she was participating in a marathon: *"…but everybody's reaction was like, are we running the marathon? [laughs]*" [Nafisa, Interview 2], implying that running a marathon was not the 'normal' expected social order for South Asian women. Nafisa's account, thus, suggested two aspects; that there was a change in the way some female South Asian groups were viewing sport and exercise; and that there were other female South Asians who engaged in role distancing, detaching themselves from "*the South Asian side*" when they participated in sport, such as running.

For Nafisa, engaging in an active lifestyle was not perceived to be "*negative*" by her mother, which implied that taking part in running could be perceived as stigmatising for some South Asians, who did not conform to cultural and gender role expectations. Using Goffman's (1963) analysis on stigma, it could be argued that for some, participating in exercise and sport was discrediting to their identity as South Asian women. Evidence (Ahmad, 2011) has indicated that the potential for personal discrimination from members of the same community group tended to occur when South Asian women's participation was questioned or condemned by their community. It seemed that, in order to engage in sport and/or exercise, female South Asians needed to detach themselves from their gender and cultural 'South Asian' role. Nafisa described how she was alerted to the distinct lack of female representation in the South Asian running community:

> *"I remember my neighbour, I went for a practice 5k run and he saw me there, and he was really shocked that I was doing this [practice 5k run] cos he's Bengali and his*

wife's traditional, and he was like: 'oh my God, I've never seen an Asian woman running before', then I realised, he was right that you don't [see South Asian women running]" [Nafisa, Interview 2]

In this account, Nafisa illustrated that there were cultural and gender biases in outdoor running in some South Asian communities. Her male neighbour was really shocked to see an Asian woman running. Applying Goffman's (1959) analysis would indicate that a "*practice 5k run*" was not part of the 'normal' expected social order for women in some South Asian communities, thus shocking her male neighbour. Nafisa explicitly stated that her male neighbour's wife was "*traditional*", suggesting that his wife conformed to the "*traditional*" values of South Asian Bengali womanhood.

Nafisa and Lubna also emphasised the role of sport and/or exercise in their lifestyle and by involving themselves in outdoor sporting activities, including training for marathons and running, they did not conform to all the traditional gender roles available in their South Asian cultures. According to Goffman (1959), some social roles are more important to the individual (or performer and/or actor), depending upon the context. In this case, performing as a sporting woman, who identified as South Asian and presenting such an image to others in their communities (or their audience) was particularly meaningful for both Nafisa and Lubna. Andersson (2002) (see section 2.3.2), who investigated how Norwegian-Pakistani girls aimed to change how they were perceived by others in their communities through involvement in sport, found that by challenging traditional gender identities through sport participation, her respondents disputed the shared stereotypes of the South Asian minority in present-day Norwegian society. In the current research, when asked how she felt about being a sporting South Asian woman with asthma, Lubna replied: "*I'd say empowering because you often don't see it [South Asian women and/ or girls engaging in sport and/ or exercise], particularly in South Asian cultures"* [Lubna, Interview 2]. For Nafisa, participating in a 5k run was a means to help increase representation of South Asian Punjabi women to others: *"for me, it was like representation when I did the 5k [run]. I was representing Punjabis, not Westerners, that's how I see it"* [Nafisa, Interview 2]. Thus, by participating in sport and challenging their cultural and gender identities, Lubna and Nafisa distanced themselves from the role of a 'traditional' South Asian woman and contested their gender role expectations. As mentioned previously (see section 5.5; "Other South Asians are lazy": Challenging cultural standards'), this may have been because Lubna received support from her parent(s) and was socialised to integrate a sporting

role with her South Asian role.

Nafisa was particularly surprised when she participated in the 5k run and saw other South Asian women taking part, which indicated that other South Asian women were beginning to engage in outdoor running:

> *"I thought I was the only one when I got there, it was women, it was the breast cancer run, so there was quite a few [South Asian women]"* [Nafisa, Interview 2].

She contemplated why there was greater engagement from South Asian women during the breast cancer run:

> *"…lots of [South Asian] people did the walk as well; they were encouraged to do it. Since then, a lot of [South Asian] people have done it, I don't see why it's an issue at all and I don't see why it should be"* [Nafisa, Interview 2]

Nafisa believed that there was greater engagement because they were "*encouraged to do it*". This traced back to her previous accounts, where she suggested that South Asian women were not encouraged to engage in sport and/or exercise. Nafisa explained that, when South Asian women were encouraged to take part, it created a ripple effect, fostering greater engagement from others. It seemed that other women were also contesting their cultural and gender role expectations as South Asian women and taking part in exercise and/or sport after being encouraged to do so. Although it was unclear who encouraged these women to participate in this 5k run, Nafisa's account demonstrated how a supportive role from significant others can be important for South Asian women and that sport and/or exercise participation was becoming part of the 'normal' social order.

5.7.2.1 Summary

This subordinate theme highlighted some of the reasons why some South Asian women did not engage in sport and/or exercise. For example, they were less likely to participate in outdoor sport and/or exercise because they might have found it uncomfortable to do so. This seemed to be related to their gender and cultural role expectations. Nafisa's accounts suggested that some South Asian women might be aware of how others in their community perceive them. Nafisa emphasised the role of clothing for South Asian sporting women, particularly for those who wanted to engage in outdoor sport and/or exercise. In Nafisa's account, her use of jogging bottoms, a hoodie and a t-shirt, were used to present her modest appearance to others. By

following her gender and cultural role expectations to dress modestly, Nafisa decreased the risk of stigma. Further, using Zeiler's (2010) insights, the current research argued that the body might have appeared as 'dys-functional' to Nafisa if she was wearing, what was deemed to be, inappropriate clothing.

From Lubna's and Nafisa's accounts, it was suggested that South Asian men and women were socialised differently and had different gender role expectations. Men were socialised to engage in sport, whereas women were encouraged to take part in non-sporting activities, according to Lubna and Nafisa. When applying Goffman's (1959) insights, it was evident that it was part of the expected social order for men to play football and other sports and when women took part in exercise and sport, this was considered 'shocking' in some cases. An example from Nafisa, who described her male neighbour being surprised at her participation, exemplified the view that women were not expected to take part in sport. Commensurate with previous evidence (SportScotland, 2001; Lawton et al., 2006; Sriskantharajah & Kai, 2007; Grace et al., 2008), Nafisa suggested that emphasis was placed on South Asian women to prioritise family responsibilities and for them to attend to domestic chores.

By taking part in sport and exercise, Nafisa, Dhaya and Lubna contested their gender and cultural role expectations. It seemed that other South Asian women were also challenging their cultural and gender role expectations and taking part in exercise and/or sport after being encouraged to do so. Thus, the evidence in this subordinate theme has revealed that attitudes towards sport and/or exercise were beginning to change and that South Asian women, including Nafisa and Lubna, were engaging in acts of role distancing (Goffman, 1959) by taking part in sport and/or exercise. The final superordinate theme switches focus and moves onto the participants' accounts, with regard to their relationships with their HCPs.

5.8 Relationships with healthcare professionals (HCPs)

Participants, from their perspective, described their interactions with their HCPs. This included sharing their experiences with their GPs, doctors, or asthma nurses. The patient-healthcare provider relationship can be conceptualised from an SI perspective (Shattell, 2004). In essence, this means that individuals (in this case, the patients and healthcare providers) interpret the environment based on symbols and meaning (Shattell, 2004). This influences how they act (Shattell, 2004). In the current research, when the participants sought medical assistance, they performed the role of 'asthma patient'. Using Goffman's (1967) theoretical insights about 'rules

of conduct' during social encounters, this superordinate theme is split into two subordinate themes and investigates how participants' present their 'asthma patient' self in the HCP-patient relationship. The first subordinate theme explores some of the positive relationships between participants and their HCPs, which were characterised by a collaborative partnership. The second subordinate theme (see section 5.8.2) contrasted with the first, with some participants remaining sceptical of their HCP's assistance and advice.

5.8.1 Engaging in a therapeutic relationship

The participants in this subordinate theme, including Nafisa, Kalan, Lubna, Priti, Indiana, Tasneem and Jamal, presented themselves as credible and knowledgeable individuals who were invested in their health. This coincides with the concept of the 'expert patient' (Department of Health, online, 2001). The term, 'expert patient', was first acknowledged in a parliamentary report, which was about a 'healthy citizen' initiative developed to help people manage their chronic illness (Department of Health, online, 1999). The report stated that expert patient programmes were about *"…developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness*" (Department of Health, online, 2001, p. 3). This subordinate theme was characterised by a supportive working relationship and seemed to encompass a therapeutic interpersonal alliance between the participants and their HCPs. As discussed in section 2.2.5, a therapeutic relationship is defined as one which is perceived as caring and supportive and embedded in a safe, comfortable and non-judgemental environment (Mottram, 2009). These relationships can extend over a period of time or last briefly (Priebe & McCabe, 2006). A therapeutic relationship is one where the HCP demonstrates friendliness, genuine interest, and empathy, along with the desire to facilitate and support patients (Cousin et al., 2011). Consequently, these types of relationships can engender interactions which facilitate effective communication between the patient and HCP, and are thus, considered as the primary component of positive patient-HCP experiences.

Nafisa and Kalan, described their relationships with their HCPs:

> *"I'm really happy because they [asthma nurses] talk to me and they're happy to agree with me when I say: 'I really think I need it [preventer inhaler]'. There was a period after [giving birth to] my daughter where I was using it [reliever inhaler] a bit more and then I went in [to the surgery] and I said: 'look, I am using it [reliever inhaler], this is probably once a week, what do you think?, do you think I should get back on the*

preventers?'" [Nafisa, Interview 1]

Nafisa explained that her HCPs engaged in a therapeutic relationship with her by having a reciprocal discussion with her. They 'talked' to her, listened to her and seemed to value her opinions. Nafisa's HCPs provided a supportive environment for her, one which enabled her to speak openly about her asthma concerns and to seek advice. The HCP delivered a patient-centric style of consultation for Nafisa. More recently, there has been a shift towards patient-centred care, where the HCP-patient consultation is based on open communication, listening, and exploring the patient's experiences to understand more about the patient's illness trajectory (Begum, 2015) (see section 2.2.5). Patients are encouraged to be actively involved in their care (Begum, 2015) and should be given the opportunity to be 'expert patients' (Department of Health, 2011). In this interaction, Nafisa's HCP encouraged Nafisa to be an 'expert patient'. The 'expert patient', like the 'expert doctor' is seen as reasonable and rational, where the patient informs the doctor about what he/she believes is wrong and what needs to be addressed (Stokes, Dixon-Woods & Williams, 2006). This ties in neatly with the GINA guidelines (GINA, online, 2018), which states that patients and HCPs should be involved in a patient-centric type relationship. In the current research, Nafisa's asthma nurse offered her advice:

> *"…she [asthma nurse] said: 'well, that's actually nothing [referring to Nafisa's use of her reliever inhaler], let's see how you go for a month, keep an eye on yourself, see how often you're using it and if you need it more, then we'll get you back on [to the preventer inhaler] and we <u>did</u> have that conversation*" [Nafisa, Interview 1]

In this account, the asthma nurse helped Nafisa to understand more about her condition and also eased Nafisa's concerns about her use of the reliever inhaler. Further, Nafisa's account demonstrated the asthma nurse's trust in Nafisa to track her use of the reliever inhaler and monitor her symptoms and her condition. Nafisa believed that the freedom to self-manage her condition enabled her to do "*quite well*":

> *"…I feel like I manage quite well but that's because they're [HCPs] allowing me to manage myself too and they're giving me that <u>choice</u>, but I know there are other doctors that probably don't do that…"* [Nafisa, Interview 1]

Nafisa suggested that her HCPs trust her and gave her the "*choice*" to manage herself. From an

SI perspective, it is possible that Nafisa and her HCP share the same 'definition of the situation' (see section 3.2) during their consultation. As mentioned previously (see section 5.6.1; 'Finding the right balance'), the definition of the situation is about how people understand the social context of their interactions, and through the definition of the situation, he/she learns how to behave appropriately (Altheide, 2000). For example, in a healthcare encounter with a HCP, the patient is expected to reveal details about his/her illness, and the HCP is expected to treat the patient accordingly (Stokes et al., 2006). In Nafisa's case, the definition of the situation related to her interactions with her HCPs in her asthma reviews. Both Nafisa and her asthma nurse worked together to improve Nafisa's self-management of asthma and for her to manage her condition effectively. A trusting relationship between Nafisa and her HCP enabled *"…a feeling of working together to achieve the aim of better self-management"* (Pinnock, 2015, p. 2) (see section 2.2.5).

Goffman (1967) proposed that there is a ceremonial order or rules of conduct in social interactions, arguing that there are formal and informal rules, which are interwoven to represent the ceremonial order of the interaction. Previous studies (e.g., Strong, 1979; 1988) investigated this in the doctor- patient relationship. It was found that both the doctor and patient had an idealised public character, where the doctor was clinically competent and where patients were expected to acknowledge and appreciate their expert authority (Strong, 1979; 1988). If this was followed, patients were perceived as 'good', and doctors were expected to respond in a respectful and polite manner (Strong, 1979; 1988). This evidence, however, is outdated and was conducted at a time when doctors were held in high esteem. More recent evidence from Stokes et al. (2006) argued that both doctors and patients use 'rules of conduct' in the doctor-patient relationship. Stokes et al. (2006) reported that doctors and patients typify each other as either, 'good' or 'bad', and this is dependent on whether each party adheres to or breaks the 'unwritten rules of conduct' (see Stokes, Dixon-Woods & McKinley, 2003). In Stokes et al.'s (2006) study, 'good' doctors were perceived as being polite and honest to patients, caring and competent, and who valued personal care. These perceptions were interpreted as rules of conduct by the patients, demonstrating the dramaturgy of the relationship, interaction and symbolism. Goffman's (1967) insights in the current research would suggest that the rules of conduct related to the trusting relationship between Nafisa and her nurse. Nafisa's HCP seemed to value her opinion and had faith in her ability to manage her condition. This is 'self-management', as defined within many asthma protocols, where the patient receives education

to allow them to understand and therefore manipulate treatment to ensure they manage their asthma well (Pinnock, 2015). Although Nafisa did not explicitly state whether this type of behaviour constituted a 'good' HCP, she mentioned that she was happy with her care. This suggested that Nafisa was content with the way her asthma nurse interacted with her. In the same way, although Nafisa did not indicate what a 'bad' HCP was, she implied that there were other doctors who may not permit their patients to manage themselves or provide them with the choice to do so. Similarly, to Nafisa, Kalan's experience with his general practitioner (GP) was indicative of a collaborative relationship between the patient (in this case, Kalan) and GP:

> *"…if it's a new GP who wanted to try a new regime of medication: 'fine, let's give it a go, let's take a look at it, if there's any benefit'. He [GP] wanted to switch to a more daily low dosage maintenance kind of thing, but to me it served no purpose: 'fine, we'll leave it alone and go back to that' [previous treatment approach]"* [Kalan, Interview 1]

At first, Kalan was initially supportive of the idea of trying out a new regime of medication set by his GP. When Kalan found that the medicine "*served no purpose*" to him, his GP listened and respected his opinion. In this interaction, Kalan was presenting himself as knowledgeable and competent with regard to his asthma self-management. Like Nafisa, it seemed that Kalan was given the opportunity to be an 'expert patient', when he discussed his treatment approach with his GP. There was a shared responsibility, rather than a didactic relationship. This is important for therapeutic relationship development and demonstrates that the HCP-patient relationship is moving on from the 'doctor knows best' model and the 'old' expected social order, where doctors gave advice and patients were not as involved in their care, as depicted in Moore's (2009) research on the Nepalese medical system.

In 2012, the Department of Health (online, 2012) published a report titled, 'Liberating the NHS: No decision about me, without me' (p. 1). This is an initiative developed to place the patient's preferences at the core of shared decision making along the patient pathway; in primary care, before a diagnosis, at referral and after a diagnosis (Ham, Charles & Welling, 2018). In Kalan's account, the decision to remain on the same treatment regime was made in discussion between Kalan and his GP. In SI terms, Kalan was staking his claim to be an equal in the clinical encounter and his GP was receptive to this. Although the GP has years of training and experience, Kalan has a deep understanding of asthma self-management with his personal experience of the condition. Alongside the GP's training, Kalan's knowledge was used to inform his treatment

approach, thus allowing Kalan to stake his claim as an equal. Kalan believed that the HCP-patient relationship can be improved if the patient engages in effective self-management of asthma:

> *"I also think it's a sense that the doctor realises that you're competent enough to deal with self-management, which I think makes their life much easier as well*" [Kalan, Interview 1]

> *"…so you can have that discussion where I felt: 'okay, I don't need this medication', but because <u>he</u> realises that I was managing my asthma, that I had my parameters set up, that I knew what I was doing, it became <u>less</u> of a discussion around him [his GP] having to tell me what I needed to do…"* [Kalan, Interview 1]

According to Kalan, the patient plays a significant role in establishing a therapeutic relationship with their HCPs (Geppert & Collazo, 1998; Newell & Jordan, 2015; Kornhaber et al., 2016) (see section 2.2.5). Kalan indicated that his self-management of asthma enabled his doctor to believe that he was capable of managing his condition (Pinnock, 2015). This allowed Kalan and his doctor to discuss his treatment approach. The dialogue in Kalan's account demonstrated that his doctor felt less inclined to dictate what was required of Kalan to manage his condition. This was presumably because Kalan was already engaging in self-management behaviours and was happy to manage his asthma. In Stokes et al.'s (2006) study, both the patient and doctor had mutual obligations. For example, from the patient's perspective, doctors were obliged to be prompt and provide high-quality care (Stokes et al., 2006). From the doctor's perspective, patients were obliged to accept the doctor's guidance and authoritative position (Stokes et al., 2006). In the current research and in terms of the rules of conduct (Goffman, 1967) between the patient and the GP, Kalan's account illustrated that there were rules for obligations on both sides which have to be fulfilled. Kalan suggested that the patient has obligations to follow, including having an understanding about how to manage asthma. By following these obligations, Kalan's GP reciprocated by dictating less in the consultation. Similarly, to Nafisa's account of her relationship with her HCP, Kalan's relationship with his GP became one characterised by shared decision making and trust.

Kalan indicated that a "*good*" doctor was one who was approachable to the patient: *"if you've got a good doctor that you can talk to and who understands asthma, that's fine"* [Kalan, Interview 1]. The doctor was typified by Kalan as "*good*", if he/she trusted their patients'

intuition and validated their patients' subjective experiences; *"I think most doctors, the good ones will probably say the patient does understand their body better"* [Kalan, Interview 1]. This coincides with the Department of Health's (2001) report, which stated that HCPs who are involved in long-term follow up care with patients who have chronic illness, should acknowledge that patients understand their condition better than the HCPs themselves. It is perhaps important then that the HCPs 'role performances' (Goffman, 1959) as 'treaters' are seen to embrace active involvement from patients. For Nafisa and Kalan, having the support of practitioners and engaging in a communicative relationship were considered important features of the therapeutic relationship. Indiana and Lubna suggested that communication was particularly significant when it came to discussing asthma medication in the consultation:

> *"…the doctors say you should take it [preventer inhaler] daily and when I went for that visit, probably a couple of months ago because it [asthma] had worsened, they actually told me the reason…"* [Indiana, Interview 2]

> *"…they [doctors] tell you to take it [preventer inhaler] twice a day to build that up in your system, but I used to not take it until I needed it. I've got a bit better now, I try and take it every day"* [Indiana, Interview 2]

After Indiana suffered an asthma attack, she visited her HCPs. In her accounts, she explained that her doctors helped her to understand more about the role of the preventer and reliever inhaler and the reason why she was required to use her preventer inhaler twice a day. Indiana suggested that this information helped her acknowledge the importance of taking her preventative medication regularly. Education was key to enhancing the therapeutic relationship between Indiana and her HCP. Without this understanding, she may not have been inclined to play the role (Goffman, 1959) of the 'adherent patient' and could have suffered poor control and another asthma attack. Applying Leder's (1990) 'absent' body insights would indicate that Indiana sought to treat her asthma-body whilst it remained in a 'dis-appearing' state, or an 'absent' bodily state of awareness. As explained in section 5.3 ('Managing medication'), the preventer inhaler was used by some participants to target the 'dys-appearing' body, rather than the 'absent' body (Leder, 1990). Indiana's account clearly demonstrated that education is integral to adherence. Previous to this consultation, Indiana stated that she did not understand much about her treatment approach; *"I didn't really understand too much*" [Indiana, Interview 1]. She went on to say that she felt like this was: *"good advice…when you hear from a doctor,*

you kind of take it more don't you? [Indiana, Interview 1]. According to Indiana, receiving this type of information from a doctor bears significance and credibility, illustrating how her doctor's words were both powerful and meaningful during the interaction. Lubna shared a similar perspective:

> *"…about four years ago, I noticed that the doctors' explained to me I was doing [using] my inhaler completely wrong and I was like, all THOSE YEARS I THOUGHT I WAS USING IT RIGHT. I think it's because I grew up and I understood more about asthma …the doctors felt like they could explain it to me better, they can explain to me how to use an inhaler and how to manage it better, so I became better at it. I became like a better patient…"* [Lubna, Interview 1]

In her account, Lubna spoke in a louder tone when she described her astonishment that she had not been using her inhalers correctly. Evidence has suggested that people need to be taught approximately every 6 months to ensure they maintain an effective inhaler technique (Braido et al., 2016). When Lubna was unaware that she knew less about asthma and that her inhaler technique was wrong, Lubna may have been perceived as someone who was unknowledgeable in the consultation. After learning that her inhaler technique was *"completely wrong*", Lubna used her doctors' advice to practice her inhaler technique. This allowed her to become what she perceived to be, a "*better patient*", or as someone who tried to be better at managing their asthma. Drawing on Goffman's (1959) self-presentational insights indicated that Lubna's performance of self was influenced by her 'patienthood' role. Lubna's role performance as a 'patient' was improved when she became more knowledgeable about managing her asthma and she could now present herself as someone who understands how to use her inhaler correctly. If, for example, the role expectations of an asthmatic patient relate to being adherent, then Lubna's and Indiana's HCPs helped them to fulfil these role obligations when they educated them about their medications. Their adherent medication taking behaviour consequently may have helped Lubna and Indiana to enact idealised role performances as 'adherent patients' in further consultations, and possibly, as 'good' patients in their HCPs view. The latter was unclear, and further research is required in order to understand the HCPs perspective.

For Priti, a friendly and caring style role performance from her HCPs helped create a positive consultation experience: *"…they [Priti's HCPs] were really nice, they said take your inhaler*

regularly and don't do too much sports" [Priti, Interview 1]. After experiencing an asthma attack (see section 5.6.1; 'Finding the right balance'), Priti's HCPs advised her about her medication and sporting activity in a "*nice*" manner, which Priti took on board:

> *"[the HCPs said]: 'don't do too much vigorous sports but do build it up, don't go straight into the hard stuff', which I didn't"* [Priti, Interview 2]

> *"[the advice] really helped cos I haven't had a major asthma attack ever after that, so if I feel out of breath [when exercising], I take the pump and I feel better"* [Priti, Interview 2]

In her follow up interview, Priti elaborated on her HCPs advice. It was clear that Priti accepted the guidance offered to her, where they recommended that she use her reliever inhaler during exercise and/or sport. As mentioned previously, pre-dosing before sport and/or exercise has been advocated by Asthma UK (2019a), NHS (2019), BTS guidelines (2016) and GINA (2018). This helped her to incorporate her sporting identity carefully with her asthma-self. Priti's account illustrated that self- management education, on behalf of the practitioners, included educating the patient about the medical management of asthma and other aspects of the patient's life, such as sport and exercise management, particularly when the sporting-self is threatened by asthma. Tasneem described the consequences of having a 'threatened' sporting identity below. She discussed how a nurse helped her with this:

> *"…every single year, I used to run 200 metres at school. It was a record for me. I felt worried that I wouldn't be able to do something that I'd wanted to do because of asthma, because this one illness is holding me back*" [Tasneem, Interview 1]

Tasneem's account suggested that she feared that her asthma-self would threaten her sporting identity. At the time, she viewed her asthma-self as "*holding*" her back from competing. Her sporting accomplishments were also at risk. To help her retain her sporting identity, she sought advice from her HCPs, demonstrating her trust in their judgement:

> *"…that's when I spoke to a nurse at the doctor's surgery, she's the one that showed me the breathing techniques, and she explained to me: 'when you need a break, you need to take a break, don't carry on, so take part in it, but if you feel like you need to drop out or you need to take a break, you need to take it'"* [Tasneem, Interview 1]

As part of engaging in a therapeutic relationship and providing a holistic approach to healthcare, Tasneem's nurse understood and appreciated the significance of being able to play sport for her patient. It seemed that as part of the nurse's role performance and role obligations, providing healthcare in an empathetic and instructive manner was of importance. Recognising that she was playing the role of the 'treater' in this interaction, the nurse acknowledged that Tasneem was facing challenges accommodating asthma into her sporting lifestyle and understood that this challenged Tasneem's sporting identity. She permitted her to take part in a sporting event, which was clearly very important to Tasneem. The nurse thus re-negotiated her role as 'treater' and combined professional clinical competence with relational skills. The nurse played an integral role in maintaining important aspects of Tasneem's identity, including her asthma and sporting identity. In doing so, she fulfilled her role obligations to provide a patient-centric approach in her interaction with Tasneem, which helped Tasneem develop her asthma management skills during sport. The nurse taught Tasneem about her breathing ability and also suggested that she takes breaks mid-performance to protect herself from experiencing a 'dys-functional' body (Leder, 1990). In a previous subordinate theme (see section 5.6.1; 'Finding the right balance'), Tasneem's accounts indicated that taking breaks and using the reliever inhaler mid-performance were not considered 'markers' of an unsuccessful performance of the sporting-self. It is possible that Tasneem's nurse played a role in this, when she advised Tasneem to take breaks mid-performance if required. Tasneem stated that this technique allowed her to compete in the 200 metres: *"I took part in it… I was fine"* [Tasneem, Interview 1]. Another participant, Jamal, spoke of his admiration for his GP: *"Dr. Mussa[20] and he's well nice so every time I go… he'll ask how everyone is and kind of have conversations whilst you're talking to him"* [Jamal, Interview 1]. However, Jamal's GP did not seem to appreciate how Jamal's sporting identity was affected by his asthma-body-self:

> *"…if I go gym and I'm proper pushing myself, so one of the top notches on the running machines so I'm pretty much sprinting for a minute or two minutes, and when my heart's proper pacing, my chest is getting wheezy, manage your breathing, control your oxygen intake and what you're getting out, that definitely helps a lot more"* [Jamal, Interview 1]
>
> *"I spoke to the doctors about that and they were like: 'don't push yourself too hard, cos*

[20] All names used throughout this thesis are pseudonyms.

if you if you go too intense, you're not helping your chest and you're not helping your breathing and it can be quite bad"" [Jamal, Interview 1]

Similarly, to Tasneem, Jamal indicated that he attempted to control his breathing during exercise to improve his sporting progress. He experienced symptoms of asthma and his body began to 'dys- appear' (Leder, 1990). There was a stark difference between how Jamal's asthma-body-self appeared to his doctor and to himself. When Jamal pushed himself physically, his body appeared to him as 'eu-static' (Zeiler, 2010) instead of 'dys-functional' (Leder, 1990). This was because Jamal believed that he was controlling his "*oxygen intake*". Jamal had a perceived sense of control of his asthma-body-self during his sporting performance. The doctors, on the other hand, seemed to undermine his sporting performance and cautioned him about pushing himself "*too hard*", perhaps unaware that Jamal viewed his body as being in 'eu-statis' (Zeiler, 2010), where he was able to control his breathing during his sporting performance. Jamal stated that it was unfortunate that his family doctor restricted him from pushing himself in the gym: *"so for him [Dr. Mussa] to be like: 'aw, yeah, just don't push yourself too hard', it's a bit peak [unfortunate]"* [Jamal, Interview 1].

5.8.1.1 Summary

All of the participants in this subordinate theme seemed to value the opinions of their HCPs, with the exception of Jamal, who was frustrated at the lack of a holistic approach from his family doctor. The participants' accounts identified some of the characteristics of a therapeutic, interpersonal relationship. Relationships were characterised by trust, mutual respect and valuing the opinions of each other. Participants were encouraged to be involved in their care and some were provided with the opportunity to be 'expert patients', aligning with the Department of Health's (2001) recommendations. From a SI perspective, the definition of the situation was agreed upon by both parties. Further, when applying Goffman's (1967) analysis on the ceremonial order or rules of conduct and Stokes et al.'s (2006) insights, the current research revealed that trust was indicative of someone who was a 'good' doctor. The participants accounts suggested that it was important for HCPs to embrace active involvement from their asthma patients, as part of their role performances as 'treaters' in consultations. Additionally, a friendly and caring style role performance from HCPs helped create positive consultation

experiences. For example, Priti's HCPs advised her about her medication and sporting activity in a pleasant manner. Priti's account also demonstrated that self-management education, on behalf of the practitioners, should include educating the patient about treatment, as well as how to cope with other aspects, such as sport and exercise management. Also, the current research found that Tasneem's HCP re-negotiated her role as 'treater' and combined professional clinical competence with relational skills. The HCP's role performance as 'treater' included being compassionate and empathetic to Tasneem, which helped enable her to develop asthma management skills during sport.

The present study revealed that the patient's sporting identity might not always be appreciated by HCPs. In Jamal's case, his HCPs did not view his sporting progress positively and cautioned him about pushing himself in the gym. This leads to the final subordinate theme, 'Unmet expectations of care', which explores the perceived characteristics of non-therapeutic relationships with HCPs from Reena's, Dhaya's, Faheema's and Samina's perspective.

5.8.2 Unmet expectations of care

In this subordinate theme, the HCP-patient relationship was characterised by disillusionment and dissatisfaction with asthma care. For example, HCPs were perceived as being unhelpful, ignoring the patient's perspectives, and having different care objectives by Samina, Faheema, Reena and Dhaya. This meant that the HCPs in this subordinate theme failed to deliver therapeutic relationships with the participants. In Samina's case, her HCPs failed to let her have agency and maintained their powerful position as professionals when they failed to listen to or validate her opinions. Using a SI perspective and Goffman's (1959) insights on role performance and rules of conduct, this subordinate theme explores the expectations that Reena, Faheema, Dhaya and Samina had of their HCPs and investigates how these participants assessed their social encounters with their HCPs.

In Samina's account, the HCPs failed to provide her with the opportunity to be an 'expert patient' and failed to let her have agency. Samina had recently been hospitalised after experiencing an asthma attack. At the hospital, Samina explained that she was often ignored by her HCPs:

> *"…the <u>whole</u> time I was ill, I <u>knew</u> from the start what was wrong with me, and I knew what they were going to give me as in the [treatment] next step and what I needed, but the doctors refused to acknowledge my opinion. My exam was on acute bronchitis <u>which</u>*

I knew I had, but they refused to listen to me" [Samina, Interview 1]

In complete contrast to Nafisa and Kalan's accounts (see section 5.8.1; 'Engaging in a therapeutic relationship'), Samina reported feeling unacknowledged by her doctors, despite understanding which treatment approach she required and presenting herself as someone who was knowledgeable about her condition. As discussed in section 5.8.1, an effective therapeutic relationship encourages patients with asthma to be involved in discussions about their treatment (GINA, online, 2018). Samina indicated that she was not involved in this discussion. Although Samina presented herself as knowledgeable about her condition, her personal understanding was unacknowledged by her doctors. Here, the context of the situation should be considered. In Nafisa and Kalan's accounts, these were much calmer discussions because Nafisa's and Kalan's asthma was under control. This fits with Leder's (1990) insights, as Nafisa's and Kalan's asthma-body was in a 'dis-appearing' bodily state of awareness. In Samina's case, this was a high stress situation because Samina was experiencing an asthma attack, or a 'dys-functional' body (Leder, 1990). In this situation, the HCPs were presumably anxious to find out what was wrong with Samina. From a SI perspective and using Mead's (1934) conceptualisation of the 'I' and 'me', it is possible that the 'I' took over the 'me' in this high stress environment, where Samina's condition was critical. Although the HCPs knew how to act, their 'me' may have been disrupted because of the stressful environment. In SI terms, the 'normal' expected social order did not exist because emergency situations are very different to managed consultations. On the other hand, it could be argued that Samina's HCPs displayed their authority in the encounter by failing to listen to her perspective. Charles, Gafni and Whelan (2000) argued, that from a SI standpoint, doctors have more power than patients to structure the interaction. This can make patients feel that their voice is silenced or stripped of meaning during the interaction (Charles et al., 2000). However, Charles et al.'s (2000) study only looked at interactions between patients and HCPs in general practice. When compared to emergency situations, managed appointments are much more structured in terms of a 'normal' expected social order.

As mentioned in the previous subordinate theme (see section 5.8.1; 'Engaging in a therapeutic relationship'), the doctor-patient relationship is governed by unwritten rules of conduct (Goffman, 1967; Stokes et al., 2006). In Samina's case, the rules of conduct pertaining to HCPs listening to and respecting their patient's opinions were broken when Samina's HCPs refused to listen to her or provide her with the opportunity to be an 'expert patient'. Goffman (1967) argued that rules of conduct can either be reciprocal or lack reciprocity. The latter occurs when

individuals' express patterns of power distribution (Goffman, 1967), or what Ditton (1980) referred to as a 'micro politics' of the social order. When Samina's opinion was 'silenced' (Charles et al., 2000), she became critical of the medical care received and questioned her HCPs authority in the interaction:

> *"…they [hospital doctors] didn't know <u>what</u> was wrong with me, they <u>kept</u> giving me courses of prednisolone and I was like: '<u>this is gonna have really bad side effects'</u> because it causes weight gain and all sorts of stuff and makes you more hungry and long-term, its [prednisolone] side effects are <u>really</u> bad, so I was like, I don't wanna be taking [prednisolone] again and again and again and again because it's not <u>needed</u>"* [Samina, Interview 1]

In Samina's opinion, her doctors treated her inappropriately with courses of prednisolone. In response, Samina vented her anger at repeatedly being prescribed prednisolone, which she perceived as unnecessary. From a clinical perspective, Samina's HCPs followed a protocol for asthma management; they were following an algorithm for management which denotes prednisolone, as recommended by the BTS (2016) guidelines. Samina's experience was characterised by disillusionment with her HCPs', which was exacerbated by her unwillingness to take the prednisolone. It seemed that treatment of prednisolone was imposed rather than agreed upon, with Samina having little opportunity to participate in her clinical decisions. Prednisolone can have side effects, but it can also be lifesaving (NHS, 2019). It is possible that Samina's HCPs were fulfilling their role obligations (Goffman, 1959) as 'treaters' by prescribing prednisolone, as it is considered to be standard procedure for acute asthma management (BTS, 2016). However, they may not have been fulfilling their obligations when they did not involve Samina in her treatment plan and failed to provide her with the opportunity to express her concerns. Dhaya and Faheema described how their HCPs failed to meaningfully interact with them:

> *"I think a lot of doctors don't really know, <u>they</u> just say you've got asthma, but they don't know how to help, they don't know what to <u>say</u> to you, it's just you've got asthma, here are your inhalers and that's it, they <u>have</u> that check-up every year, but <u>other</u> than that I think that's just it, they just leave you to it"* [Dhaya, Interview 1]

Dhaya believed that some doctors were unhelpful and did not understand how to interact with their asthmatic patients. She suggested that they lack meaningful interaction with patients of

asthma. Hussein and Partridge (2002) (see section 2.2.5) reported that many of their South Asian respondents were unhappy with their GPs and were concerned that their GPs did not provide sufficient information about asthma. This highlights an important consideration about educating HCPs about how to work with South Asian adult patients with asthma. According to Dhaya, doctors failed to offer any further assistance, other than offering inhalers and assuming that the patient will take responsibility for their condition. Yet, this is contrary to self-management education and advice, which states that HCPs hold a responsibility to ensure that each of their patients with asthma has personalised advice about their condition to help them self-manage their condition effectively (Pinnock, 2015). Dhaya suggested that asthma was minimised by some doctors:

> *"I think they [doctors] don't see it as that serious, they just say: 'well unless you're having regular asthma attacks, you don't really have a problem'…"* [Dhaya, Interview 1]

From a clinical perspective, if someone is not experiencing regular asthma attacks, it normally means that their asthma is under control and they do not require further intervention (NHS, 2018c). On the other hand, when someone is experiencing recurrent attacks, it usually denotes a lack of control and either poor compliance with medication, or wrongly diagnosed treatment (NHS, 2018c). Using Goffman's (1959) insights on role performance, it seemed that Dhaya believed that her HCPs evaded their rule obligations as 'treaters' to provide every asthmatic patient with assistance, irrespective of the patient's asthma status. Leder's (1990) phenomenologically-inspired insights (see section 3.5.1) would suggest that HCPs are more concerned when the patient is experiencing a 'dys-functional' body, that is, when a patient experiences an asthma attack. Zeiler (2010) (see section 3.5.2) argued that when the body appears to the person as painful, it commands attention from HCPs, who then aim to treat bodily 'dys-appearance' in order for bodily 'dis-appearance' to occur (Leder, 1990; Zeiler, 2010). According to Dhaya, being in a state of asthma bodily 'dis-appearance' (Leder, 1990) was minimised by doctors. Faheema shared a similar view:

> *"I've had appointments where they've told me to come in, they wanna see whether I've still got asthma or not, so they tell me to meet up with a nurse for spirometry and then I go to the appointment and the nurse doesn't know how to do it, so after waiting ages for that appointment, they tell me to come back another time, so I'm like: 'okay', and*

then on the day of the appointment, they tell me that it's been cancelled" [Faheema, Interview 1]

"…you know how they tell us that someone with asthma should get checked regularly to see how they're getting along with their medication, that's not been happening with me, and I can't be bothered to make an appointment because I feel like they're not gonna do anything and it's just a bit stupid" [Faheema, Interview 1]

Faheema's account was overt with frustration. It emphasised the importance of the HCPs rule obligations as 'treaters', which is to render appropriate medical services to patients (Stokes et al., 2006). In the current research, Faheema followed her role obligation as a 'asthma patient' to attend her appointment, believing that she was following the recommended advice about being checked for her asthma. The HCPs, however, committed a rule breach (Stokes et al., 2006). In essence, it is possible that the rules of conduct were broken when Faheema's HCPs turned her away. Faheema described her long-standing disagreement with her HCPs about the way her consultations have been handled:

"I go to the appointment and the nurse doesn't know how to do it, so after waiting ages for that appointment, they tell me to come back another time" [Faheema, Interview 1]

Despite this rule breach, Faheema tried to fulfil her obligation again by attending another appointment. From Faheema's perspective, the HCPs failed to fulfil their obligations. Faheema perceived that she did not receive the care that she had expected to. In response, she ended her relationship with her HCP. According to Stokes et al. (2006), the breach of rule obligation to provide medical assistance can be repaired using Goffman's (1967) analysis on 'corrective interchange'. To correct the situation, Goffman (1967) considered four phases; challenge; offering; acceptance and thanks (see Figure 9, p. 284, below).

Challenge: attention is called to the misconduct by first party
Offering: the other party repairs the breach (e.g., by an apology)
Acceptance: the first party accepts offering of the other party
Thanks: the other party thanks the first party

Figure 9. Goffman's (1967) 'corrective interchange', as cited in Stokes et. al (2006, p. 14).

Challenge: HCPs contact Faheema for a re-appointment	*"I've had appointments where they've told me to come in…"* (as quoted above)
Offering: Faheema attends appointment	*"…they tell me to meet up with a nurse for spirometry and <u>then</u> I go to the appointment…"*
Acceptance: Faheema accepts HCPs help	*"…they tell me to come back another time, so I'm like: '<u>okay</u>'…"*
Thanks: (In Faheema's case, this step did not occur because her appointment was cancelled, and her HCPs breached their role obligations to provide care)	

Figure 10. Adaptation of Goffman's (1967) 'corrective interchange' in the HCP-patient relationship for Faheema.

In Faheema's account, there was no indication that the HCP attempted to repair the relationship after Faheema stopped attending her appointments. It was unclear how Faheema's HCPs felt about these particular interactions, indicating that both views may be beneficial to understand how to correct the situation. For example, where Stokes et al. (2006) investigated both the patient's and doctor's perspectives, the current research did not, and it remained unclear how Faheema's HCPs defined the situation. In previous evidence (e.g., Hussein & Partridge, 2002), it has been reported that some South Asian respondents were dissatisfied

when they were unable to see their GP. Similarly, to the current research, Hussein and Partridge (2002) did not investigate the HCPs viewpoints, instead limiting it to the patients' perceptions. In Faheema's and Dhaya's case, a lack of confidence in practitioners, and unmet expectations of care seemed to lead to a resistance towards visiting their HCPs. In a follow-up email a year after her first interview, Dhaya stated that she had not attended any other appointments for her asthma:

> *"I haven't been to any asthma appointments since I did the [first] interview, so I think they probably took me off the register, plus I changed GP, so no one's really checked the asthma, neither have I had any issues that I needed to go to the GP for*" [Dhaya, email, 27/06/18]

Although Dhaya believed that she did not have any "*issues*" with her asthma, this suggested that both the patient and GP believed her asthma played a minor role in her everyday life. Dhaya chose not to attend any asthma appointments and her GP seemed to exclude the basic assessments.

Reena suggested that she did not attend her appointments because she had different goals to her HCP: *"…back then, I didn't attend any of them it's just for me, it was just a waste of time, I just had no interest to be honest*" [Reena, Interview 2]. Reena provided a fuller perspective below:

> *"…when I do that puffy thing [peak flow meter], it only comes to about 250 to 300 and then they give you all this advice and how you could make it better, and I <u>know</u> they're the professionals, and they know about asthma, and I think as long as I know how to take the inhaler properly, I'm not interested, it's not arrogance, I don't have time to go and do reviews and get told the same thing over and over again, I'm just not interested really*" [Reena, Interview 2]

In Reena's account, it was evident that she did not want to be told what to do with regard to her asthma care. Unlike Samina, Dhaya and Faheema, who seemed to want additional care, though it was unclear how they wanted to be cared for, Reena did not want her HCP's advice. Reena acknowledged that her HCPs were the "*professionals*". Unlike Samina, when Reena recognised that her HCPs were the professionals, she did not question their authority (Stokes et al., 2006). Instead, Reena queried the way her consultations were conducted. Reena indicated that the repetitive guidance of the "*professionals*" stopped her from visiting them.

Although asthma patients have certain rule obligations, including attending annual asthma reviews, Reena breached this rule obligation when she chose not to attend. This seemed to be related to Reena's perceived sense of control of her asthma and her belief that she did not require help or advice from her HCPs. When she did attend, Reena described how she followed "*protocol*" in her asthma reviews:

> *"…she's [HCP] going through what is necessary for her cos that's her profession, that's her job, but I've really wasted 20 minutes of her time haven't I?,... so I think it it's a bit rude of me in the sense of, I'm doing it because its protocol, or because its procedure, or it's what you do, isn't it?"* [Reena, Interview 1]

In this account, Reena explained that she followed "*protocol*" and "*procedure*" because that is how asthma patients are required to behave in their reviews. Whilst performing the 'asthma patient' role, Reena suggested that she adhered to her HCPs' measures because it is what is expected of her during the consultation. Drawing on Goffman's (1959) theoretical insights would indicate that the general social order in an asthma review included taking a peak flow meter reading, where the HCP offered guidance about asthma. Reena suggested that the HCP was going through the objective measures because it was her job to do so. Reena completed the tasks in order to respect the social order of the asthma review. In SI terms, this indicated that Reena and her HCPs did not share the same definition of the situation (see section 3.2). Although Reena attended her asthma review as per her role obligations as an 'asthma patient' and engaged in the consultation as part of the social order, this did not necessarily mean that she was engaging in it because she agreed with her HCP's definition of the situation. Instead, she perceived herself as being "*rude*" because there was no agreed definition of the situation, though the HCP may not have been aware of this. A failure to interpret the consultation or definition of the situation in the same way seemed to lead to interactional problems when Reena became disinterested with the way her consultation was being handled. Reena emphasised how there was a lack of consensus about her asthma in her interactions with her HCPs:

> *"When you do go [to the asthma review], there's less emphasis on what you're actually trying to achieve, so when you go in and you explain everything, you do their measures, and then they'll explain to you, how do you feel, that's pointless. I feel like I'm wasting their time because I know that I'm not gonna go and do that inhaler twice at morning*

and twice at night" [Reena, Interview 2]

When Reena visited her HCP, she noted that there was "*less emphasis*" on her own objectives. Instead, the consultation seemed to be focused on completing the clinician's measures. Applying Goffman's (1959) insights would indicate that, in this specific interaction with her HCP, Reena carried out a 'contrived' performance of the 'patient' role by completing the HCP's measures and fulfilled the role expectations of the 'patient' role. Reena believed that the asthma review should not include repetitive guidance about asthma. From Reena's point of view, her HCP seemed to think differently. From a clinical perspective, a peak flow meter reading of 250-300 may signal due cause for further intervention, although this depended on Reena's normal, or usual peak flow reading (Pinnock, 2015). Goffman's (1959) insights would suggest that Reena withdrew from the interaction altogether, rather than play a 'contrived' performance of her role as an 'asthma patient' for her HCP. Since there was no agreed 'definition of the situation' between Reena and her HCP, this ultimately led to interactional problems and relationship breakdown.

Further, Reena's account demonstrated that her HCPs asked her about how she felt about her asthma status, though, this only served to frustrate Reena, who viewed this exchange as "*pointless*" (as quoted above). Reena had a perceived sense of control of her asthma and considered herself knowledgeable in relation to controlling her condition. This perceived sense of control and lack of reciprocity in perspective between Reena and her HCPs influenced her treatment behaviour. In Reena's case, the HCP informed her of potential ways to improve her peak flow meter reading, assuming that she would take her medication regularly. Reena, on the other hand, knew that she would not adhere to her medication regime. Thus, the HCP's guidance seemed "*pointless*" to Reena because she had a different definition of the situation (in this case, the asthma review). Additionally, Goffman's (1959) self-presentational insights would suggest that Reena's performance was 'contrived' in this interaction because she knew, prior to her role performance as an 'asthma patient' in the review, that the advice from her HCP would be "*pointless*". Thus, her 'asthma patient' role performance was contrived for the sake of following the social order in the asthma review.

The expectations of care also link to the definition of the situation; if both the patient and HCP have different definitions of the situation, they may also have different expectations of each other in the consultation. For example, Reena's HCP may have been expecting her to adhere to her medication regime, whereas Reena seemed to be frustrated at the lack of emphasis on what

she was trying to achieve. Reena suggested that if her HCPs discovered that she was not adhering to her medication, she would "*be in trouble*":

> *"if they [HCPs] find out, I'll be in trouble probably, they always send me clinic letters and symbicort, but I try and manage it more naturally"* [Reena, Interview 1].

It seemed that Reena was trying to distance herself from using her inhalers, yet the HCP was aiming to improve her peak flow meter reading based on the assumption that Reena would adhere to her medications. Reena hinted that she did not disclose her intentional non-adherence and her decision to use non-pharmacological treatments to her HCPs. This raises a further issue in the HCP-patient relationship, whereby Reena concealed information from her HCPs. Goffman (1972) argued that people commonly act to preserve their dignity and self-esteem in order to 'save face'. In the current research, this could mean that Reena concealed information about her medication taking behaviour because she would have liked to present herself as someone who adhered to her medication regime and was perceived as a 'good' patient in her HCPs view. In doing so, it is possible that she tried to 'save face' (Goffman, 1959) and preserve self as a 'good' patient by keeping this information from her HCPs because it was part of the 'normal' expected social order to take medication regularly.

Since Reena did not do so, she kept this information concealed because she did not want her HCPs to view her presentation of asthmatic and/or patient self as 'inept' (Schott, 1979, p. 1325). Her actions were also consistent with the results of a UK parliamentary report, which indicated that patients were less likely to tell their orthodox medical practitioners that they were using alternative approaches and that they were making their own decisions about whether to use medical treatment (House of Lords, 2000).

5.8.2.1 Summary

For Reena, Dhaya, Samina and Faheema, a therapeutic relationship did not seem to exist. Samina's relationship with her HCPs, for example, involved a lack of consideration for her personal understanding of her illness. In complete contrast to Nafisa and Kalan, who in the previous subordinate theme (see section 5.8.1), suggested that they were involved in their treatment approach, it seemed that treatment was imposed on Samina rather than agreed upon, with Samina's opinions being dismissed several times.

Additionally, Faheema's and Dhaya's accounts demonstrated how the HCP-patient relationship

was about managing expectations. From Faheema's and Dhaya's perspectives, perceived unmet expectations of care led them to end their relationships with their HCPs. There was a failure from both to understand the interaction from the others perspective. Therefore, it was deemed that the rules of conduct were not followed, and the interaction failed. When applying Goffman's (1959) theoretical insights, it was suggested that Faheema's experiences with her HCPs were impacted by various rule breaches. A breach of obligation to provide appropriate medical care, for example, led to frustration on Faheema's part. An attempt to repair this breach by her HCPs was not described by Faheema, though, Goffman's (1959) concept of 'corrective interchange' could be used to see if the patient-HCP relationship could be repaired.

Further, using a SI perspective, Reena's accounts revealed that the HCP and patient can have differing definitions of the situation with regard to the asthma review. Goffman's (1959) analysis indicated that Reena presented a 'contrived' performance of self during the consultation, when she engaged in her HCP's objective measures in order to 'save face'. The HCP, however, may not have been aware that Reena was presenting a 'contrived' performance, making the consultation ineffective for both parties. There was a lack of reciprocity of perspective between Reena and her HCPs; in SI terms, there was no agreed definition of the situation. In contrast to the previous subordinate theme (see section 5.8.1; 'Engaging in a therapeutic relationship'), it seemed that Reena had different objectives in the asthma review, which decreased the chances of a therapeutic relationship.

To conclude, together with the previous subordinate theme (see section 5.8.1), therapeutic relationships involved the patient and HCP having similar care objectives. The HCP also provided the patient with the opportunity to be an 'expert patient' (Department of Health, 2001). By using Goffman's (1963) analysis on the rules of conduct, this superordinate theme has established that therapeutic relationships involve both the patient and HCP fulfilling their role obligations and following the unspoken rules of conduct. This includes the patient and HCP listening to and respecting each other's opinions and where the HCP encourages involvement from the patient in their care.

In contrast, non-therapeutic relationships related to consultations where the patient and HCP had differing views on care objectives. On the basis of these findings, it is possible that a shared understanding between the patient and HCP is required in order for both parties to achieve their objectives. There were also various rule breaches from both patients and HCPs, which led

to unmet expectations of care. The opportunity for patients to act as 'expert patients' was also not implemented by HCPs in non-therapeutic relationships. In order to build a therapeutic relationship, the patient's expertise should be valued and applied in their care approach. By recognising this, the HCP may be able to manage expectations of care more effectively.

5.9 Conclusion

This chapter has presented an IPA analysis of UK-resident South Asian adults experiences of asthma and sport and/or exercise, in the form of seven superordinate themes and several subordinate themes. The findings were conceptualised using Goffman's (1959; 1961; 1963) analysis on self- presentation and stigma, together with Leder's (1990) and Zeiler's (2010) phenomenologically- inspired insights, which contributed to a nuanced understanding of the participants' experiences of asthma, sport and/or exercise.

The findings explored how participants negotiated their asthmatic identity and engaged in 'passing' behaviours and 'role distancing' (Goffman, 1959). The accounts also revealed how participants managed and experimented with preventer and reliever medication and how some participants sought out alternative non-pharmacological treatments, which aligned with their cultural identity. Participants' accounts demonstrated that some participants had to deal with cultural stigmatisation from other members of their South Asian communities, in terms of asthma and sport and/or exercise participation. The findings also discovered that some participants challenged their South Asian cultural and gender identities and engaged in role distancing when they engaged in sport and/or exercise. The latter focused on South Asian women's gender identities and the ways in which this was negotiated, so that they were able to take part in exercise and/or sport without feeling stigmatised. In terms of asthma, sport and/or exercise participation, the findings suggested that participants were self-conscious of the presentation of their sporting-self. This meant that they searched for ways to enact an 'idealised' performance of sporting-self by finding the right balance. Lastly, the participants' described their experiences with their HCPs, which explored the perceived characteristics of therapeutic and non-therapeutic relationships.

The next chapter (chapter Six) represents some of the participants' accounts in poetic form, using an alternative arts-based approach known as 'Poetic inquiry'. Following on from chapter Six, the final chapter (chapter Seven) draws together the research findings and presents a conclusion to the study.

Chapter Six:

"Eyes streaming, asthma would be going off":

Using poetic inquiry in asthma and exercise and sport research in the UK-resident South Asian population: An alternative representation

6.1 Introduction

Following on from the previous chapter which discussed seven key superordinate themes, this chapter presents eight poems constructed from the participants' interview transcripts from the current research. This process is known as poetic inquiry. Miller (2018) argued that poetic inquiry was emotionally engaging, and this approach allowed me to interpret, present and communicate their findings in an expressive manner. There has been a growing interest in the field of poetic inquiry in the field of chronic illness. To date, however, there has been a scarce amount of published participant-voiced poetry in the literature, focusing on asthma and sport (see Owton, 2012). Moreover, there has been no participant-voiced poetry focusing on UK-resident South Asian adults and their experiences of asthma, sport and/or exercise in the research literature. Thus, the poems in this chapter aim to provide an ongoing dialogue of participants' experiences, in an attempt to *'let [the participants'] stories breathe* (Frank, 2010). The poems aim to be engaging and evocative and promote the visceral experience of asthma, sport and exercise.

6.2 I can’t breathe, I’m gonna die

used to participate in a lot

activities that involved exercise

diagnosed properly, fifteen, sixteen

became quite severe

sixteen to eighteen

my asthma was quite bad

running up the stairs start off

anxiety attacks diagnosed

with anxiety

part of a football team, five years had

to drop out of football couldn’t control

it, panic attacks end up in hospital, I

passed out body went blue, stopped

breathing

mum was like no, don’t exercise anymore

felt really bad, can’t even exercise

part of a dance group, breakdancing, street dancing

had to drop out of dance

really passionate about dance, dance is all I live for, love dancing I

can remember, dance rehearsals

really bad asthma attacks

every single time, start hyperventilating

every single time

face would go bright red

I can't breathe

it's always the asthma

the doctors are like 'she's hyperventilating'

'you need to calm down, you need to calm down'

but I can't calm down

I can't breathe, I'm gonna die

that's what I think every single time

breathe, the only thing that's going through my head

choking on your own breath

it's a horrible feeling, it's just so horrible

feel like you're gonna die

you hear all these stories, this person died

stuff like that GETS to me

what if that happens to me one day

not gonna be able to control myself, breathing, it's your body if

you can't control it, you're dead

[Tasneem, self-identified as having moderate asthma]

Tasneem described the difficulty of working with a 'dys-appearing' or 'dys-functional' body (Leder, 1990), when she participated in dance rehearsals and football. This poem demonstrated that Tasneem's asthma affected her sporting lifestyle and her sporting identity, which included being part of a dance group and a football team. It is possible that Tasneem's asthma identity affected her sporting identity when she had to drop out of her football and dance groups. The physical and emotional distress caused by her symptoms was evident in this poem, when her mother asked her to stop engaging in sport

because of her hospitalisations. The assault of asthma upon the body gave rise to feelings of panic (Allen-Collinson & Owton, 2014, p. 14) for Tasneem, who tried to control her body, though she was unable to remain calm. There was a sense of resentment towards her asthma, when she stated that it was "*always*" her asthma that caused these feelings of panic and fear. The fear of death preoccupied Tasneem's mind and locked her in a state of panic. Tasneem was forced by her asthma to reconcile herself to her own death. Tasneem's preoccupation with and fear of death from asthma resonated throughout the poem. This expression of feeling 'horrible' because of asthma was also described by Maryam. In her poem below, Maryam vividly depicted the visceral experience of asthma:

6.3 That's asthma

burning sensation in my throat

really bad cough, really dry

makes me vomit

couldn't even speak

cough in every second

hurt my chest, that's asthma

I'm just gonna die, all my organs coming out

nose blocked, mucus in my throat

watery eyes

horrible, ahhhh horrible

[Maryam, self-identified as having intermittent asthma]

The sensuous nature of asthma was illustrated by Maryam, who evocatively described the interplay of coughing, vomiting and mucous production, which seemed to stop her from breathing appropriately. Like Tasneem, Maryam felt as though she might "*die*" from asthma. This apprehension of death was pertinent in other participants' experiences of asthma. Samina detailed her experience of an asthma attack, which happened whilst she was falling asleep (see p. 282).

6.4 What if I don’t wake up the next morning?

getting into deep sleep

just falling asleep

my chest, I could feel

everything gathering up

like when you see them movies

something’s, someone’s getting closed up into a web or

a door’s closing, closing, closing

like that

that feeling of your airways getting so tight

having no oxygen

what if I don’t wake up the next morning

reaching out for my inhalers in my sleep feel

like you’re sinking at the same time

in shock

oh my God, what the hell is happening

shit, what just happened

plays with your mind

don’t know if this is just my mindset

sometimes think

is it worth thinking about the future

don’t know if you’re going to wake up the next morning

because you suffer from it

SHOULDN'T think like that ah

shit

[Samina, self-identified as having moderate asthma]

Comparable to Tasneem and Maryam, Samina was fearful about what her condition might lead to. In Samina's poem, the fear of death from asthma impacted the way she thought about her life. Samina was anxious about her future and blamed herself for this type of precarious thinking. In contrast to Tasneem's experience, Samina's poem was connected to the way the asthma attack occurred; that it happened whilst she was falling asleep, and at a point when she was already losing control of her body. The question of whether she would wake up the next morning is powerful in itself and demonstrated the complete loss of control she had of her body and also her future. When Samina referred to her asthma as 'it', this suggested that her asthma-body was perceived as an object other than self; an "*alien presence*" (Leder, 1990, p. 73). Zeiler (2010, p. 9) argued that when an individual experiences a hurting body part as 'it' and the pain gets worse, the individual might not "*trust*" their own body. This seemed to be the case for Samina, when she started to question whether she would be alive the next morning. This attempt at retaining agency of the body with asthma is illustrated in the next poem by Samina (see p. 284), albeit from a different perspective.

6.5 The feeling… was just not right

noticed from the age of sixteen

became exercise-induced

every time I'd do exercise, need my inhalers

really struggle

used to go swimming that

was really difficult

especially going underwater

still to today, cannot do it

I can't breathe through my nose, so…

kind of stopped exercising

the feeling after an asthma attack was just not right I

didn't like it

exercise tolerance has dropped

struggle to go up a flight of stairs

weakness

me being ill is the worst feeling ever

from the first day till I recovered,

all I'd done was cry, so stressed, so upset

tried every Indian remedy

ginger, lemon, honey, black pepper, made to chew raw cardamom

horrible porridge, disgusting

you do not wanna know how I felt [laughter]

started going Zumba

first class, out every five minutes taking my inhaler

now, kind of take it before and once in the middle I'm

okay, getting better

I feel happy

[Samina]

This poem is structured in a way that described Samina's experiences from diagnosis to the present day. After discovering that her asthma was exercise-induced, Samina accepted that her breathing ability did not allow her to engage in some activities, including swimming underwater. She wanted to build up her exercise tolerance. Similarly, to Tasneem, the struggle for taken-for-granted tasks including walking up a flight of stairs, demonstrated how asthma can bring "*weakness*" onto the body. The emotional toll it takes was illustrated in this poem; "*all I'd done was cry, so stressed, so upset*". However, by building up her exercise tolerance and not having to rely on her inhaler as much during Zumba, Samina was able to "*feel happy*". This might be because Samina successfully integrated her asthma with her choice of exercise (see section 5.6.1). In the following poem (see p. 286), Reena described her "*fight*" for control, where she described learning how to fight with her body, instead of using her reliever inhaler to treat her symptoms.

6.6 Fight through it

exposed to asthma at a young age

my mum wouldn't let me take a pump, didn't want me to have a pump

she used traditional methods, wasn't a very good experience

brown sugar and turmeric

sit there holding onto the sofa, not being able to breathe

mum's trying to give you turmeric and brown sugar [laughs]

believe it or not

it did used to work

used to take the edge off asthma really well

brown sugar makes it easier, sweeter easier

pill to swallow, so to speak

no western medicine whatsoever

when I was swimming, it used to flare my asthma

Mum used to be frantic by the time I got home eyes

streaming, asthma would be going off

didn't let it bother me, it'd just be like 'aw I'm wheezing'

makes your body tougher, carry on with my day

get home, Mum will give me some haldi [turmeric]

that will be it really

my exercise doesn't trigger my asthma it's

only if I go really intense

if I'm doing intense training, running or jogging by

the end, I do have to take my inhaler

I stopped exercising for a while

my asthma got really bad I

couldn't do it

now I'm getting back into it

do a lot of walking, try running two, three miles a day, a bit of fit training

run, sprint, run, sprint, run, sprint

that does trigger my asthma

you need to be regularly breathing, learn some techniques

learnt differently

I mean my mum's not really going to give me an inhaler I

had to learn to fight through it

the symptoms, just try and calm your body down

just think about what you're doing

not allow yourself to get overwhelmed by it, you don't have a choice

[Reena, self-identified as having intermittent asthma]

This poem is about how Reena was taught not to depend on "*western medicine*", even after experiencing symptoms during sport. In Reena's case, the carnal nature of sport and asthma is considered; "*eyes streaming, asthma would be going off*". There was the metaphor of fighting with her symptoms or fighting "*through*" it. Reena's poem also showed how her response to asthma was influenced by her South Asian cultural identity. This related to her use of non-pharmacological treatments or "*traditional methods*". By only having turmeric and brown sugar to treat her symptoms when she was younger, Reena was forced to learn how to keep control of her body; "*I had to learn to fight through it, the symptoms, just try and calm your body down, just think about what you're doing, not allow yourself to get overwhelmed by it, you don't have a choice".* Additionally, this 'fighting' attitude seemed to imply that she valued this way of treating asthma; "*didn't let it bother me, it'd*

just be like 'aw I'm wheezing', makes your body tougher, carry on with my day, get home, Mum will give me some haldi [turmeric], that will be it really". This is in contrast to Samina, who used her reliever inhaler to treat her symptoms, even though she had tried other non-pharmacological treatments. The following poem (see p. 288) detailed Priti's perspective, who thought that her asthma was "*gone*", yet, experienced a sudden recurrence of symptoms after she started exercising.

6.7 I thought the asthma was gone

I had it when I was like five

it got worse when I started doing exercise I

was going to the gym a lot

on that week, I went there the whole day of the week

the cardio stuff, running, triggered it

run for an hour outside, then thirty minutes in the gym my

muscles tiring, my chest and back really hurting after I did

my cardio, it really hurt

that's what made it, triggered the asthma attack

then I had a asthma attack

it happened in the night I

couldn't sleep

I couldn't breathe properly

my chest really hurt, it felt really tight

I started wheezing, really hard to breathe

couldn't really speak

don't really like home remedies

lime water when I'm sick

don't drink that much, just take the inhaler

inhaler works for me, quicker

went to the doctors in the morning

gave me this mask, attached to oxygen or something

pumping something

I just stopped doing exercise, going to the gym I

thought the asthma was gone but no…

[Priti, self-identified as having mild asthma]

Priti's poem emphasised the deteriorating effect that asthma can have on the body. Priti's story began when she discovered that she was experiencing an asthma attack after a prolonged period of exercising. This poem created a picture of what was happening during the attack, where Priti's muscles were hurting and her body was in pain. She became wheezy and breathless and lost control of her bodily movements; "*I couldn't sleep, I couldn't breathe properly, my chest really hurt, it felt really tight, I started wheezing, really hard to breathe, couldn't really speak*". Unlike Reena's poem, Priti's poem showed that she preferred using her inhaler to treat her symptoms, instead of fighting the body with "*home remedies*". When she visited the doctors, the depiction of Priti being handed a mask, where she was being pumped with oxygen builds a powerful image of her experience. Having an exercise-induced asthma attack led her to make the decision to stop exercising. In the next poem (see p. 290), Enayah evocatively described how having asthma disrupted her sporting lifestyle and how it was experienced as a "*constant battle*".

6.8 That constant battle

some people can't do what I can

it is good, that to some extent, I can a

feel-good factor

but then

it can be quite depressing when

it's there and I want to body's

saying no chance you're not

doing that today

the more you mentally prepare yourself

the more you physically can't

that can be quite depressing

that constant battle between the mind and the physical stuff

mentally it's there, mentally

it [having asthma] restricts me if I

felt a bit more healthy

if my breathing was better a lot

more I would like to do a

barrier because of it

restrictions are there

[Enayah, self-identified as having moderate asthma]

This poem related to Enayah's conflicting emotional state. It was evident that there was a mind-body split here, where Enayah was motivated to exercise, but her body was "*saying no chance*". Enayah's positivity was emphasised at the beginning of the poem when she could take part in exercise, yet there

was a sudden change of tone when she began describing the "*battle*" between her motivation to engage in exercise and the physicality of her body. Enayah switched her focus onto her physical limits and highlighted the sense of bodily restriction that came with having asthma. In the latter stages of her poem, Enayah questioned her physical state; "*if I felt a bit more healthy, if my breathing was better*". In the final poem (see p. 292), Aisha's poem emphasised the deteriorating effect that asthma can have on the body.

6.9 Feeling helpless

immune system's not very good

been ill for a couple of days

couldn't walk anymore, couldn't breathe

walking up the hill, chest felt so tight

didn't know I was having an asthma attack

daughter took me in to walk in [clinic]

one look at me

yeah, you're having an asthma attack he

was wiring me up

no, not staying in hospital

can't go home

FEEL quite vulnerable, horrible

helpless, useless

can't do anything

don't want to be in the hospital

don't want to be treated

just want a magic pill

come home, that's what I want

[Aisha, self-identified as having moderate asthma]

Aisha's poem specifically focused on the disruption that asthma can create for otherwise, independent and fully able adults. Aisha's despair and sadness was exacerbated when she had an asthma attack, which affected her independence. Treatment and hospitalisation created further disruption and she remained resistant to a hospital stay. Instead, she wanted a "*magic pill*" which

indicated that she wanted a disruption free cure or a 'quick fix' to treat her condition. This was one which did not require an extended stay in hospital and minimised disruption to her everyday life.

The poems in this article (similar to other types of qualitative and quantitative data) provided snapshots of various moments in time (Miller, 2018) for these UK-resident South Asian adults with asthma. Similar to other researchers (e.g., Kendall & Murray, 2005; Leavy, 2009; Owton, 2012; Miller, 2018), I believed that the poetic approach delivered an emotive insight into the distinctively personal experiences of my participants. According to Miller (2018, p. 5), poetry inspires a *"…slower, multisensory, and almost visceral engagement with the data",* as the readers:

> "*…approach them more slowly, expecting to hear them in their heads and being more alert to their patterns of sound, image, and ideas and more willing to engage emotionally with what is being said*" (Kendall & Murray 2005, p. 746).

These eight poems emphasised the personal experiences of life with asthma, in addition to their sporting experiences and treatment behaviours. Miles Richardson (1998) stated that *"…poetry wants us to see, to see what? those instantaneous sights, when things stand so clearly before us, when truth shows its face"* (pp. 453-454). Richardson (1998) believed that poetry is a valuable approach to research, particularly when people experience epiphanies which display humanity, and where researchers wish to recreate these experiences. In the current research, Tasneem's, Maryam's, Samina's and Priti's experiences of an asthma attack were evocatively described, and the poems were designed to strike an emotive chord to help others understand how it feels to experience such an attack on the body. The poems create a pictorial representation of asthma; one characterised by pain, angst, entrapment of the body, the search for survival and finally, the fear of death from the constriction of the body. In contrast to Tasneem's, Maryam's and Samina's poems, Reena's and Enayah's poems illustrate the "*fight*" or "*battle*" involved between the mind and body, and the negotiation of the asthma and sporting identities. In Enayah's poem, the physical state of her body was questioned several times, whereas in Reena's poem, "*fighting*" the asthma-body seemed to be a natural instinct. Also, in Reena's poem, the taste of brown sugar was elaborated upon, which added a sensory dimension to her experience. When reading Reena's poem, one might consider the "*sweet*" taste of brown sugar. Aisha, on the other hand, addressed the disruptive elements of a life with asthma. In her poem, Aisha laments the loss of her independence, particularly when she is made to stay in hospital for further treatment, sharing her desolation. The redolent depiction of a clinician "*wiring up*" Aisha builds a strong image of her experience and exemplifies the power of research poetry. According to Richardson (1998, p. 459),

the language used and the way it is used in poetry enables us to *"…find [them]selves in poems"*, making it a practical alternative or complementary approach to prose.

In terms of the poetic criterion proposed by Faulkner (2007) (see section 4.12.1, p. 157), I believed that each poem met these standards. For example, the poems were crafted to embody the experience of asthma and to direct attention to the language that evoked specific imagery and emotion for the reader; this was usually focused on the experience of an asthma attack or disruption to everyday life. Also, the poems delivered new and fresh insights about asthma. For example, Enayah's poem revealed how there is a mind-body split in reference to sport and/or exercise. Also, Samina's poem demonstrated the emotional toll asthma can have on both the body and mind. This, I believed, met the condition of 'discovery' and 'transformation', as suggested by Faulkner (2007). I now move onto my reflections about the process of research poetry and some of the relevant limitations of the poetic approach.

6.10 Reflections

This next section outlines my reflections about the use of poetic inquiry. These poems were developed from the interview transcripts and act as powerful indicators regarding the importance of the somatic senses in asthma research and the link between breathing difficulties and asthma.

One of my reflections pertained to the key difference between a poet and a research poet. According to Miller (2018), poets are more likely to cautiously consider their word selection, whereas research poets are limited by his/her participant's words, the participant's style of speaking during the interview, and their use of (or lack of) imagery and metaphorical language, emotion and evocative expressions. The words chosen by me are then edited and arranged to create a 'poem-like' piece of text (Miller, 2018). This was at times challenging for me in the current research; some interview participants spoke using emotive terminology, which made it easier to create a 'poem-like' configuration, however, it was very difficult to develop a 'poem-like' (Miller, 2018) piece for those who did not use descriptive language in their interviews.

Additionally, the author's expertise and qualifications can be questioned (Miller, 2018). For researchers who want to work in this genre, Faulkner (2007) argued that they should participate in the "*art and craft*" of poetry (p. 220). In the present study, I had only begun to have an interest in arts-based research, and consequently only recently discovered poetic inquiry. Although I was interested in the use of poetic inquiry, I did not class myself as a poet, and was new to learning this craft.

In terms of data representation, I understood that by adding a poetic representation of my participants' data in the current thesis, I was adding to the existing debates about how data can be represented in qualitative research. The poetic narratives were not intended to de-value the significance of the previous empirical evidence presented (see chapter Five), but instead, utilised to contribute to or complement with other forms of traditional data analysis such as IPA (Smith et al., 2009), as well as connect, so that there are new ways of 'knowing' and 'seeing' (Phoenix, 2010).

6.11 Conclusion

To conclude, non-traditional creative arts-based approaches and methodologies, such as poetic inquiry have challenged and modified traditional empirical research philosophies (Miller, 2018). According to Miller (2018), researchers need to participate in and support this transformation, as well as be more accepting of arts-based approaches. In this way, we must learn how to communicate research which breaks traditional boundaries, and which might prompt unforeseen, and evocative insights (Miller, 2018).

In the final chapter (chapter Seven), the main findings from chapter Five are contextualised within implications for practice. Chapter Seven also provides a conclusive statement of this thesis, including how the key themes have contributed to the field of asthma; sport and/or exercise; and South Asian-focused research.

Chapter Seven: Conclusions and Recommendations

7.1 Introduction

The overall aim of the current research was to explore the lived experiences of South Asian adults with asthma, who have, engaged or are currently engaging in sport and/or exercise and who were born in the UK or migrated to the UK at an early age. The present study explored the participants' treatment behaviour and how they managed sport and/or exercise. In this chapter, the original contributions to knowledge and recommendations for practice are outlined, followed by a discussion on future directions.

7.2 Original contribution to knowledge

The present study offered new theoretical understandings on asthma, sport and/or exercise in the UK-resident South Asian population. Goffman's (1959) conceptual analysis provided a valuable lens through which to view the asthma-self. The findings revealed that the participants were concerned about managing the presentation of their asthma-self. This was associated with Leder's (1990) insights; the participants sought to remain in an 'absent' bodily mode of awareness. The appearance of the 'dys-functional' body (Leder, 1990) was associated negatively by the participants. This fits neatly with Goffman's (1959; 1963) perspective, who argued that if a person was to act out of the 'normal' expected social order and has a discredited feature which deems them different, it increases the possibility of developing a 'spoiled' identity.

When the participants experienced a 'dys-functional' body (Leder, 1990), this did not allow them to 'pass as normal' (Goffman, 1963). In this state, the reliever inhaler became central to their performance of the asthma-self. From applying Goffman's (1959) dramaturgical analysis, the reliever inhaler was used for the following reasons: concealed or masked the asthma-body-self quickly; allowed them to shift from dys-function to either an absent (Leder, 1990) or 'eu-static' (Zeiler, 2010) bodily mode; enabled them to 'pass as normal' (Goffman, 1963). In these instances, the reliever inhaler was beneficial to the performance of the asthma-self. In contrast, when the reliever inhaler was used mid-performance in sport and/or exercise, it acted as a 'marker' of an 'undesired' (Goffman, 1959) performance. This highlights the symbolic meaning of the reliever inhaler; the inhaler was used as a vehicle for effective symptomatic relief, but also acted as a vehicle for the successful presentation of the asthma-self. The preventer inhaler did not have the same interactional benefit as the reliever inhaler. This was because there was no perceived immediate benefit commensurate to that achieved

by using reliever medication. The preventer inhaler did not mask any visible symptoms. The participants were confident in the ability of the reliever inhaler to effectively treat acute symptoms, such as sudden onset of breathlessness. This finding signifies the paradox that exists between the visible and the invisible characteristics of the condition; the visible symptoms such as wheezing, chest tightness and breathlessness and the invisible inflammation in the lungs contributing to the onset of these symptoms. If asthmatic individuals are able to comprehend the hidden inflammation, and almost visualise the inflammation occurring inside the lungs, this could lead to a better understanding of the aetiology of asthma and the basis of treatment. To reach the goal of 'eu-statis' (Zeiler, 2010) or an 'absent' body (Leder, 1990) may require this level of understanding from the patient's perspective. HCPs or healthcare policy could look for ways to strengthen the association between the preventer inhaler and treating the underlying inflammation by borrowing insights from Goffman (1959; 1963), Leder (1990) and Zeiler (2010) (see Figure 11, p. 312, below).

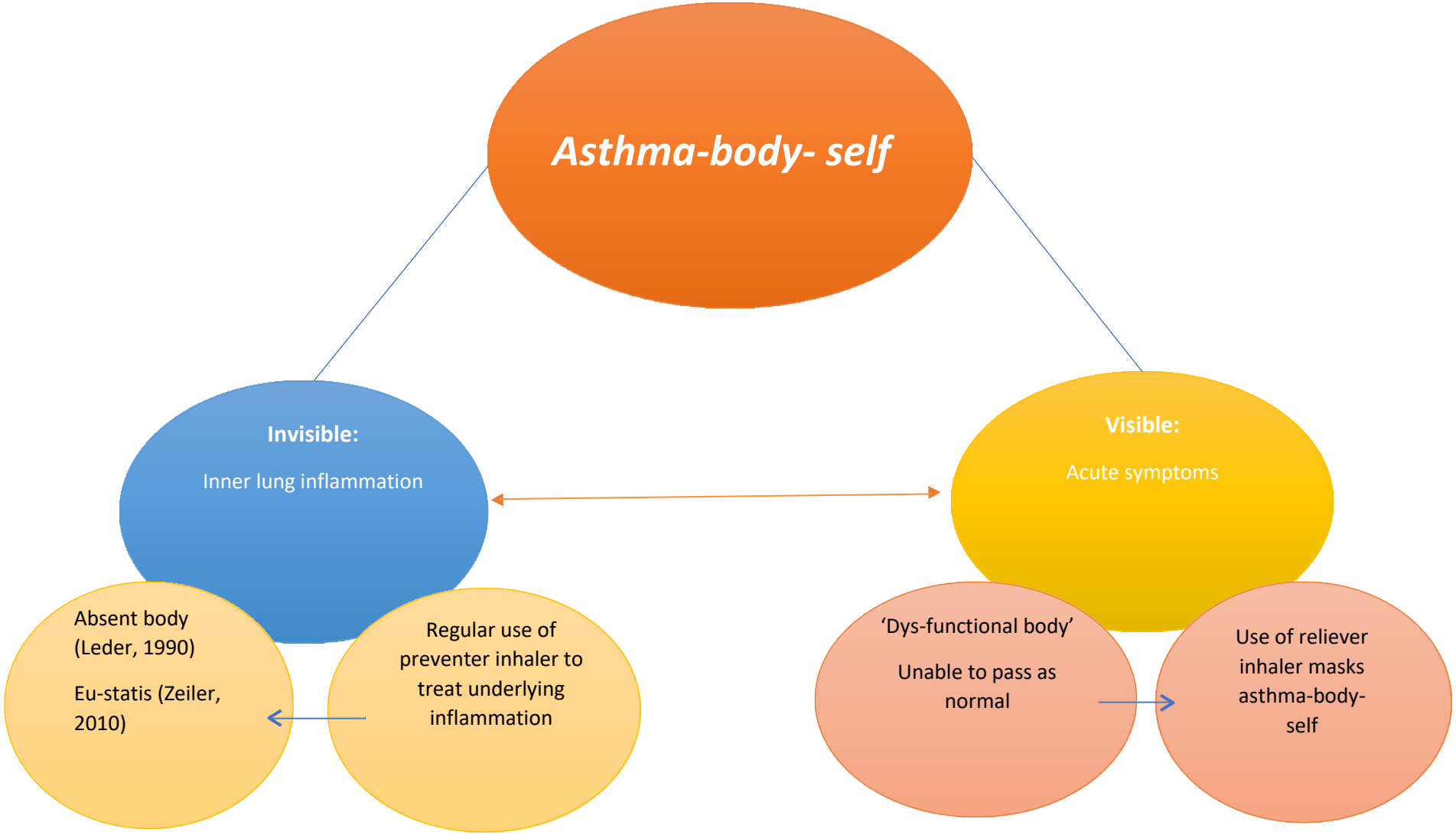

Figure 11. Alternative model of thought applying Goffman's (1959; 1963), Leder's (1990) and Zeiler's (2010) insights.

Establishing the patients' understanding of his/her condition is often a key element of the HCP consultation. Current good practice dictates that HCPs should deliver patient-centric consultations (see section 2.2.5). Drawing on the work of Goffman (1967) and Stokes et al. (2006), the present study's findings have shown that the HCP-patient relationship was influenced by 'rules of conduct'. There were interactional responsibilities on behalf of both the patient and practitioner. Shared decision making, for example, was pertinent to a successful therapeutic relationship for Kalan; an aspect which, in SI terms, enabled Kalan to stake his claim as an equal in the clinical encounter. In contrast, Reena's accounts demonstrated that a therapeutic relationship did not exist. In SI terms, there was a struggle to define the situation in her consultations. Additionally, using Goffman's (1959) analysis, there was a fear of 'losing face' and being discredited for not using her inhalers regularly. Therefore, Reena did not inform her HCPs about her use of alternative and/or non-pharmacological treatments or her non-adherent behaviour.

A functional therapeutic relationship between HCPs and their patients relies on the patient having an avenue to voice their concerns or thoughts, including what is important to them. In this research, some participants highlighted the importance of using alternative and non-pharmacological treatments. The findings revealed that alternative treatments were often linked to the participants' cultural values. Identifying cultural health practices encompasses cultural competency, or cultural respect (National Institutes for Health, online, 2017) and acknowledges one's cultural or religious identity. The approach should be one where the HCP personalises the consultation and allows the patient to speak openly about his/her cultural or religious background. The role of culture or religion is subsequently given precedence, enabling the HCP to appreciate their patient's cultural and/or religious beliefs and recognise how they play a part in their health management. Current practice suggests that HCPs should ensure that they acknowledge and respect their patients' cultural and religious values (NMC, 2015; GMC, 2019). However, it is possible that HCPs may not be able to fully understand why some South Asian patients do not adhere to their medication because they find it challenging to account for the heterogeneity of different South Asian cultures. Another possible reason might be that as part of their 'treater' role, they are generally assigned to the Western-influenced pharmacological model. In contrast, alternative treatments such as homeopathy or herbal remedies, are a feature of Eastern-influenced treatment paradigms (see section 2.2.4). By asking South Asian patients to distance themselves from their Eastern-influenced cultural values is analogous to asking the Western 'treater' HCP to distance themselves from the pharmacological model.

Non-orthodox care which includes using alternative and/or non-pharmacological treatments, often enables patients to have some control of their condition (Pike, 2005). This is important because

people who are ill can feel vulnerable, or as a "*victim of medicine*" (Frank, 1995, p. 172). On the other hand, patients who work together with their HCPs and are involved in their treatment can feel empowered because they believe that they are in control of their care (Charmaz, 2000, p. 288). In the current research, some of the participants' suggested that they used non-pharmacological treatments in order to take back some control of their condition.

The findings demonstrated the importance of recognising the South Asian population as heterogeneous. In the current research, South Asian cultures referred to Indian, Pakistani, Bangladeshi and Sri Lankan communities and their shared values. Thiara, Gill and Kelly (2010) and Singh (1994) (see section 1.9) argued that that the South Asian population is commonly perceived to be homogeneous, yet, in the current research, it was evident that there were differences between different communities. This was particularly distinct in relation to some areas, such as, stigma. This perceived homogeneity threatens to overpower the heterogeneity within South Asian communities (Thiara & Gill, 2010). In the current research, participants either referred to other South Asians heterogeneously or homogenously. The former occurred when participants spoke about cultural stigma. Maryam, for example, denoted that stigma was widespread in the Bangladeshi community, whereas Enayah explicitly stated that the UK-resident Pakistani community did not endorse asthma-related stigma. Nafisa and Kalan however, both self-identified as being British Asian, yet, Nafisa experienced stigmatisation and Kalan did not. This made it difficult to ascertain which communities Nafisa and Kalan were a part of and why Nafisa experienced stigmatisation. This demonstrates the importance of recognising the heterogeneity of South Asian ethnic groups, and to be mindful that there are differences in health beliefs and attitudes between communities, and that these differences in thought might not apply to all South Asians.

Lastly, the present study found that the 'roles' participants' performed were integral to their experiences of asthma, sport and/or exercise. For example, the findings revealed that participants directly challenged existing cultural standards. This involved engaging in acts of role distancing in various different areas of their life. For example, some detached themselves from their role expectations as 'South Asians' and participated in sport and/or exercise. Others role distanced from their asthmatic identity and their gender and cultural role expectations. This supports Goffman's (1959) analysis and the SI perspective on role theory, which propose that individuals are performing and negotiating different roles dependent on the context (Mead, 1934).

7.3 Recommendations for practice

This study aimed to identify the implications of UK-resident South Asian adults' experiences of asthma, sport and/or exercise for healthcare practice in the UK. The following suggestions and

recommendations have emerged from this study:

- Targeting cultural stigma: A better public awareness of asthma is essential for affected South Asian communities, in order for people to be correctly educated about asthma. This should include notions about the causes of asthma and the treatment of the condition, as recommended by UK healthcare practitioners. It is important to ascertain which specific South Asian groups are more likely to stigmatise asthma and who requires further education about asthma. For HCPs, understanding cultural stigma and the processes of stigmatisation may help them understand why some UK-resident South Asians do not use their inhalers appropriately, such as perceived embarrassment. Working together with policy makers, HCPs should acknowledge the cultural perceptions of asthma and the related stigma to mitigate discrimination, and develop strategies to de-stigmatise the use of inhalers and sport and/or exercise among some UK-resident South Asian groups.

- Alternative approaches to the treatment of asthma: Broader discussions about the patient's use of non-pharmacological treatments in a non-judgemental way might help inform the patient's future asthma care needs and illustrate the HCPs desire to be culturally responsive. The discussion of non-pharmacological treatments can be used as a strategy to promote a positive therapeutic relationship, which is a key aspect of contemporary practice (NMC, 2015; GMC, 2019).

- Improving the patient-HCP therapeutic relationship: HCPs might often be too quick to provide advice, without taking the time to verify what their patient already understands or what they would like to know more about. If this occurs, patients might feel as though their ability to self-manage is not adequate, leading to distrust of the HCP. Patients might also resist advice and guidance from HCPs as a result (Centre for Pharmacy Postgraduate Education (CPPE), 2019).

- It is important that HCPs openly discuss the different types of treatment approaches South Asian adults might be using to treat asthma, and more importantly, whether their patients have stopped taking their medication altogether. HCPs also need to consider whether their patients perceive themselves to be 'asthmatics' and to discuss this with their patients. It can be argued that traditionally, the management of asthma has relied on a "*recipe-like*" (Wenzel, Brillhart & Nowack, 2017, p. 1) approach of the reliever and preventer inhaler, oral steroids and other medical treatments. However, with this 'recipe-like' approach, HCPs can often believe that all of their patients will respond appropriately, as long as they adhere to the 'recipe' (Wenzel et al., 2017). In recent years, new drugs and inhalers are being

introduced in the UK, which has increased the complexity of prescribing and also contributed to the notion that patients could try different inhalers, rather than exploring or understanding the root causes behind non-adherence (Wenzel et al., 2017). The current research suggests considering patients' experiences of stigmatisation, fear of unwanted side effects and the use of alternative and/or non-pharmacological treatments. The latter of which is not part of this 'recipe-like' approach.

- Sporting and/or exercising stigma: HCPs need to be aware of the stigmatising effects of asthma on sporting and/or exercising behaviour, particularly when people with asthma engage in sport and/or exercise in front of others. There should be considerations for patient sensitivity for sporting and/or exercising people with asthma. Sporting bodies also need to acknowledge the significance of South Asian cultural and gender differences and how this might affect participation rates, specifically with regard to appearance and demeanour. The latter of which is normally associated with South Asian women.

7.4 Future directions

This study has identified and provided some foundations on which to build further research, exploring aspects of asthma, sport and exercise to improve the experiences of UK-resident South Asian adults:

- Further research is needed to expand the evidence on UK-resident sporting South Asian adults with asthma who have migrated to the UK in the later stages of life. Additional research is required about the role of sport and/or exercise for those who have previously lived in South Asia, or are 1st generation migrants.

- Supplementary research could also explore the role of specific types of sport (individual or team) and/or exercise in UK-resident South Asian groups, for example, dance troupes, running communities, yoga, swimming and/or other types of exercise.

- The current research addressed the HCP-patient relationship. This was, however, solely based on the patient's view and it did not include the HCPs perspective. Future research could be collaborative and include the 'HCP voice'. This could include several HCP perspectives, such as, general practitioners, asthma nurses, pharmacists and/or hospital staff.

- Lastly, additional research can explore how merging multi-methods (e.g., poetic inquiry) can provide alternative ways asthma and sport and/or exercise and ethnicity can be understood. Poems for example, can be co-constructed with the participants, in order to gain an in-depth outlook about the lived experience of asthma, sport and/or exercise in UK-resident South Asian groups.

7.5 Applicability of Goffman (1959; 1963) and the SI approach in this study

The applicability of Goffman's (1959; 1963) theoretical insights and the SI approach were pertinent to the current research. This was because the participants' data was often about their performance in different social roles and the intricacies of social interaction. Goffman's (1959; 1963) conceptual insights fits with the SI perspective, which proposes that social life is about symbols, such as language, gestures and appearance (see section 3.2). In the current research, the SI approach helped me to understand how the participants shaped their lifeworld as social actors. The self was thus, viewed from a micro-level analysis, instead of at a macro-level. The micro-level analysis was effective in the current research because it focuses on the smallest units of analysis; the individual (Erez & Gati, 2004). Since the aim and objectives of the present study were about individual lived experiences, this seemed the most appropriate option. The macro-level, on the other hand, includes the highest level of analysis and a broader outlook on how ideologies influence behaviour (Erez & Gati, 2004).

I chose the SI perspective and Goffman's (1959) insights over other relevant approaches, for example, the structural-functionalist approach, which is also called functionalism. This approach was influenced by the work of Durkheim (1973), who focused on social order and aimed to understand how society remains stable. It is a macro-level perspective because it focuses on how society as a whole functions, whereas symbolic interactionism explores the meaningfulness of human behaviour (Carter & Fuller, 2015). Thus, symbolic interactionists focus on how people act, and seek to determine the meanings people attribute to their actions (Dennis & Martin, 2007). In the current research, this was insightful for exploring several issues, including the use of the preventer and reliever inhaler (see section 5.3). Although social institutions, such as healthcare, attach general meaning to asthma inhalers, individuals with asthma maintain their own perceptions about what medical treatments mean to them. Whilst the functionalist approach could have been used to explore the structure of health institutions or family institutions and how this impacted people's experiences of asthma, the participants' data illustrated that it was more about the interactions with HCPs and other members of society. Therefore, the SI approach and Goffman's (1959; 1963) analysis was particularly useful in this area. Furthermore, although the functionalist approach and SI

perspective share similarities, where both advocate that individuals learn about society through socialisation in order to keep society running smoothly, functionalism does not normally encourage people to challenge their roles in society (Smith, 2010). Instead, it views active social change as undesirable. In essence, if society is functioning effectively, then people do not need to challenge their roles (Smith, 2010). This perspective assumes people conform to the different roles in society, neglecting the agency one might have (Smith, 2010). Therefore, this approach would have been less suited to explain why some participants in the current research experienced role conflict and engaged in acts of role distancing (Goffman, 1963).

The chapter now moves onto a discussion about the strengths and limitations of the present study.

7.6 Strengths, limitations and recommendations

First, although participants were sampled across South Asian communities, the present study employed a study sample of UK-resident South Asian adults with asthma, who were all well-educated. There was a lack of diversity with regard to socioeconomic background. Participant responses may have been influenced by their educational backgrounds, for example, some of the participants were enrolled in medically-scientific disciplines at university and others held employment in the healthcare sector. Despite this, one of the strengths of the sample was that it was heterogeneous in terms of ethnicity and religion. The present study, for example, included engaging with South Asian adults from different South Asian communities, including Indian, Pakistani, Bangladeshi and Sri Lankan backgrounds and with different religious beliefs (Hindu, Muslim, Sikh, Christian). This contrasts with previous studies (e.g., Hussein & Partridge, 2002). This allowed for a varied set of responses, which were possibly representative of the heterogeneity of South Asian communities in present day UK (Bhatnagar, Shaw & Foster, 2015).

The present study also included people with varying asthma characteristics, with regard to the severities of asthma and their chosen exercising and sporting activities. This presented a challenge. This is because asthma continuously varies in severity, thus, the interviews only provided a snapshot of the present time, or in this case, at the time of the interviews. It is acknowledged that interview data are constructions or stories that have been produced in the context of the research interview (Bjørnholt & Farstad, 2014). It is hoped that the richness and depth of the data compensates for the limitations in the current research. Moreover, whilst it is understood that the data in the present research are qualitatively different, there are several factors which can shape the conduct of interviews and the interactions that occur (Manderson, Bennett & Andajani Sutjahjo, 2006). This has

been discussed previously (see section 4.7.1).

Further, all of the participants were diagnosed with asthma several years ago. The majority of participants were diagnosed in childhood or adolescence. Two participants were diagnosed in adulthood, though, this was at least 10 years before the interview took place. This raises the issue that accounts may not have been accurate, since participants were tracing their experiences back from several years ago. The research found more similarities than differences across the participants' accounts, suggesting that their age of diagnosis was not a major concern.

The sample is small and self-selected, meaning that the participants may not be representative of the UK-resident South Asian adult asthmatic collective. I was therefore aware that transferability may not be applicable to other South Asian adults with asthma, who engage in sport and/or exercise.

This study focused on South Asian adults with asthma, who engaged in, or had previously engaged in sport and/ or exercise. It does not capture the experiences of those who did not take part in sport and/or exercise and their reasons for this, although the study's inclusion criteria sought to find South Asians in this category. Since there is a dearth of literature exploring UK-resident South Asian adults experiences of asthma and sport and/or exercise, this can be considered a strength of the study. There is, however, some evidence pertaining to UK-resident South Asian adults experiences of asthma, although this is also limited (see Griffiths et al., 2001; Hussein & Partridge, 2002; Griffiths et al., 2016; Ahmed et al., 2018).

The study sample included a mix of generations of 1st, 2nd and 3rd generation South Asian adults participating. This was considered a strength of the study, as the inclusion of various generations provided an insight into generational differences related to having asthma and engaging in sport and/or exercise. This is discussed in detail in chapter Five. However, only two participants who were 1st generation South Asian adults were included in the study. The majority of participants were mainly 2nd or 3rd generation South Asian adults. Most participants were young adults, ranging from 18-23 years of age. This could have potentially narrowed the scope of responses, as they had less life experience than the adults, who ranged from 36-53 years of age. Additionally, the current research did not include the experiences of UK-resident South Asian adults who had migrated to the UK at a later age, or who may have had different experiences than those who had migrated to the UK at an early age (see Netuveli et al., 2005).

Since I was unable to fluently speak other South Asian languages, such as Guajarati, Hindi, Urdu or Punjabi, the sample was restricted to South Asians who spoke English. Also, the materials were developed in English, so it is unlikely that the materials were comprehensible for South Asians who could not speak or perhaps read English. The research was therefore unable to reflect the views and experiences of South Asian adults who did not speak English. Although I attempted to reach these groups, it proved difficult. Some of the individuals approached were not comfortable with their experiences being made public and were concerned about confidentiality, thus chose not to participate. Although a reason was not provided, nor was it was required, I assumed that this was because asthma can be considered a stigma in some South Asian communities, which can deter South Asians from participating in research. This was suggested by Rooney et al. (2011) (see section 2.4). The impact of asthma-related cultural stigma is reported in the current research (see section 5.7.1). After several other attempts at recruitment, I chose to focus on the strategies which proved fruitful, such as the RPS scheme, social media advertising, and word of mouth (as discussed in section 4.4.1). Due to time restraints, I was unable to prolong recruitment.

Future research could consider targeting groups that were otherwise considered outside the reach of this PhD. For example, by targeting South Asian groups who had migrated to the UK at a later age or targeting groups who do not speak English fluently or at all. The research could consider the employment of a research assistant (RA) to complete the interviews in the participants' chosen language and transcribe them in English. The materials could also be translated into several languages for non-English UK residents. Due to financial implications, I was not in a position to employ a RA in the present study.

In spite of my intention to recruit more South Asian males with asthma, the current research only included two males who were well-educated, despite my efforts to reach out to South Asian male communities. Initially, there was some interest from this group and contact was made with me. After repeated attempts to contact the males, this proved unsuccessful when the males did not get back in touch. I assumed that the males did not want to participate and there was no contact thereafter.

The current research used self-report to explore the participants' severity of asthma. Self-report was applied to understand the participants' perspective, including how they perceive the severity of their asthma. It was used to understand how their perceived severity influences their medication taking behaviour and their experiences of sport and/or exercise. Although the

participants reported that they were asthmatic, the findings indicated that some participants negotiated their asthmatic identity and minimised their asthma status (see section 5.2). By de-emphasising the role of asthma in their lives, some participants engaged in role distancing (Goffman, 1959). Others distanced themselves from the asthmatic identity altogether, believing that they did not have 'proper asthma' (as discussed in section 5.2). This affected their medication taking behaviour when they questioned why they needed preventer medication (see section 5.3).

Although self-report furthered understanding about the participants' perceptions towards their asthma, it was indistinguishable whether participants were deemed to have controlled, partly controlled or uncontrolled asthma (as discussed in section 1.7). Additionally, it was unclear at which stage the participants were positioned at on the stepwise treatment approach (see section 1.7). In future research, it may be beneficial to ask participants' whether they understand which stage of the stepwise treatment approach they are positioned at and whether their HCPs have determined them to have controlled, partly controlled or uncontrolled asthma. This would allow a clearer overall representation of the participants' asthma state. Their clinical patterns can then be used to evaluate the differences or similarities in perspective, regarding their asthma state. Future research could ask participants to write down their medication and the researcher could place them on the correct position.

Telephone interviews via Skype were used due to the ease of access to participants (Opdenakker, 2006). Although the initial interviews were all conducted face-to-face, telephone interviews were used for two follow-up interviews with two participants. Holt (2010) suggested that telephone interviewing can often be perceived as 'second best'. However, telephone interviewing can enable a greater sense of privacy over the conversation and protect participants from being overheard or interrupted by others (Holt, 2010). It can also be a preferred method by participants when they have to discuss sensitive topics (Holt, 2010), such as their asthma. Conversely, connectivity issues affecting telephone interviewing via Skype occurred, which was frustrating for both myself and the participants. Although there were connectivity issues during the telephone interviewing via Skype, I did not incur any other issues in the current research.

7.7 Summary

This thesis explored the lived experiences of asthma, sport and/or exercise amongst UK-resident South Asian adults; a topic area which has received scarce attention in the prevailing literature, as

reflected in chapter Two. The present study thus set out to fill this gap and did so by exploring the asthmatic identity; treatment behaviours; sport and exercise experiences, including the asthma-sporting body-self; sporting stigma; cultural stigma; and lastly, therapeutic and non-therapeutic relationships with HCPs. The current research demonstrated that interactionist principles were a valuable framework for understanding and exploring the issues encountered by UK-resident South Asian adults with asthma, who have taken part in sport and/or exercise. Ultimately, this research has generated important knowledge and enhanced insights about UK-resident South Asian adults experiences of asthma, sport and/or exercise.

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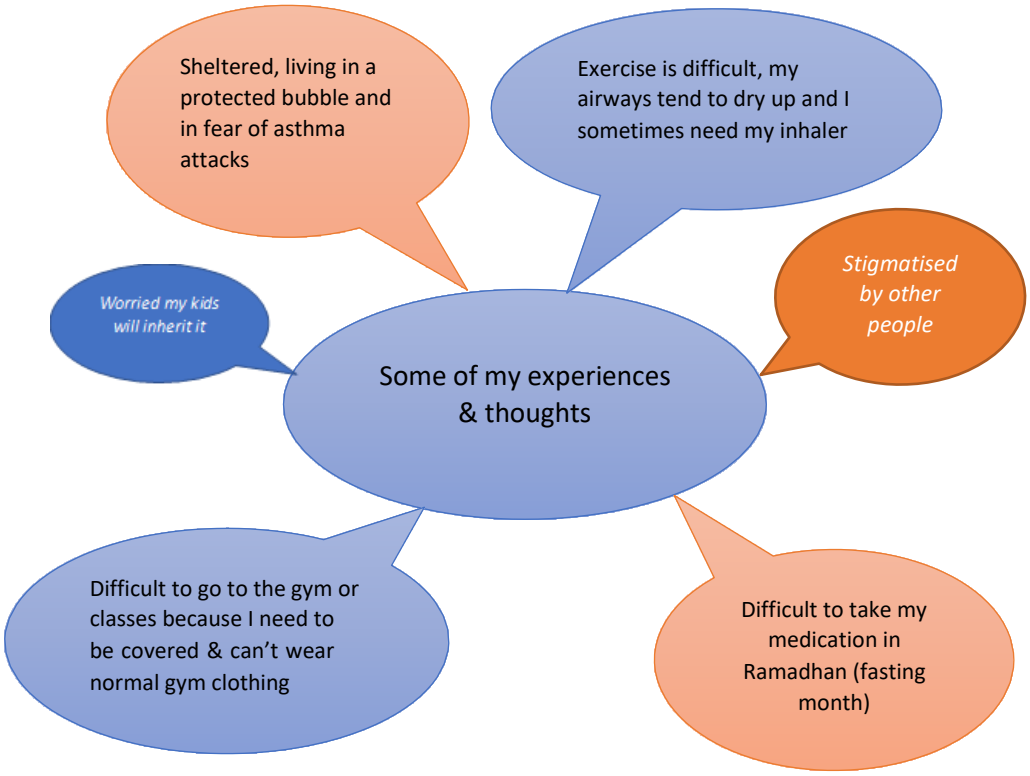
Appendices

Appendix 1: Recruitment advert

AN INTERVIEW STUDY EXPLORING SOUTH ASIAN ADULTS WITH ASTHMA AND THEIR EXERCISE/SPORTING EXPERIENCES AND ANY CHALLENGES



This study is aiming to discover and explore the experiences of South Asian adults with asthma, their sporting/exercise experiences and any challenges. You will be interviewed in a mutually comfortable place for around an hour and refreshments will be provided.

To take part, you must be South Asian, over the age of 18, able to speak English, received a diagnosis of asthma and take part in sport or exercise. You are also welcome to take part if you don't exercise or play sport as my study will involve both exercisers and non-exercisers.

Please note you will remain anonymous and all your personal information will be treated with the strictest confidentiality. Your data will **NOT** be accessible to any organisation and your interview data will remain anonymous.

WOULD YOU POTENTIALLY BE INTERESTED IN HELPING ME [A PHD RESEARCHER AT DE MONTFORT UNIVERSITY, LEICESTER] WITH MY RESEARCH?

DO YOU HAVE ASTHMA AND WOULD LIKE TO SHARE YOUR EXPERIENCES?

CHECK OUT MY WEBSITE AT WWW.ZAINABYUSUF4.WIX.COM/SOUTHASIANASTHMA

Picture courtesy of 123rf.com

MY DETAILS:

Zainab Yusuf

[PhD researcher]

E: zainab.yusuf@myemail.dmu.ac.uk

@ZainabPhD

zainabyusufPhD

Appendix 2: Interview topic guide

Version 2

10/12/2015

Interview topic guide

1. Tell me about yourself

   (History of asthma/ diagnosis/ hospitalisations)

2. Tell me about your experiences with asthma

   (Childhood experiences)

3. Can you tell me about what treatments you use?

   (*Adherence/compliance/regular medication/homeopathic medicine)*

4. Can you tell me about exercise/ sport and asthma? Your experiences?

5. Describe an asthma attack *(emotions/behaviours)*

6. [revised question] Can you tell me how it feels to be South Asian?

7. [revised question] What does being South Asian mean to you?

   Sporting lifestyle

   (Sports/ activities/barriers)

   Triggers

   (Environmental/ allergies/ exercise)

Managing asthma and triggers

(Doctor/healthcare nurse/parents/siblings)

Cultural community

(Barriers/norms & values/behaviours/thoughts)

Religious community

(Barriers/behaviours/thoughts/beliefs)

Prompts:

"That's interesting, could you tell me a little more about that?"

"I see, can you expand on that?"

"That's interesting, I would like to hear more about that"

"How do you feel when that is happening?"

"Why's that?" "What happened?"

"How did that happen?"

"Can you talk me through that experience please"

"Is it okay to talk more about that?"

Appendix 3: Participant information sheet (Researcher's copy)

Version 3

07/03/2016

An interview study exploring South Asian people with asthma and their exercise/sporting experiences

Name of investigator: Zainab Yusuf

My name is Zainab Yusuf and I am a PhD researcher based at De Montfort University in Leicester. I am interested in exploring the thoughts and ideas of asthma and its treatment in the South Asian population and would like to hear your story. I am particularly interested in how asthma and exercise impacts on your everyday life and your thoughts and ideas around this subject. If you don't exercise or play sport, I would love to know how asthma affects you and how you might treat your symptoms.

My supervisory team includes Dr. Diane Wensley, a registered nurse and senior lecturer who is based within the Division of Nursing and Midwifery at De Montfort University, Dr. Helen Owton, a certified Psychologist based at the Open University and Dr. Jacquelyn Allen-Collinson, a qualified Sociologist based at the University of Lincoln.

What is the study about?

As I mentioned previously, this study is an in-depth interview based project looking at the experiences of asthma and its treatment in people of South Asian origin. In particular I would like to explore the typical day in the life of a person with asthma, the challenges or barriers faced and any issues which may prompt support.

What does the study involve?

I am inviting you to take part in an *interview* lasting around an hour in which I (Zainab) will ask you some questions about your experiences of asthma and exercise or sport (if you exercise or play sport). You must sign and read all the necessary documentation before taking part and this will take around 15 minutes, therefore the interview process will likely take around 75 minutes. The interviews will be audio taped for the purpose of producing a verbatim (word-for-word) transcript with your permission. If you are happy to take part once you have read this sheet I will ask you to give signed consent on an accompanying consent form. This information sheet is merely to inform you about the study – there is no obligation to take part having read this through and please be assured that you will not be expected to provide a reason if you change your mind about participation.

I am aware that talking about your experiences of asthma has the potential to be rather upsetting or distressing, however there is support available from asthma specific organisations including Asthma UK and the British Lung Foundation who are trained to help you with any concerns you may have about your condition. Please remember you are not obliged to take part and can change your mind at any time during the interview. Further information is provided below.

Interviews can take place on De Montfort University campus in either the Hawthorn Building or the Kimberlin Library. If this is not possible, the interviews will take place either in a comfortable room at the sports centre or organisation you are familiar with, or a comfortable room at your religious organisation. Again, if this is not possible the interviews can take place at your home if requested. A follow-up interview may be required within two years of this interview. Please be aware that you will not be obligated to take part in the follow-up study and will not need to provide a reason if you decide not to take part. If you would like to take part in a follow-up interview, please be aware I (Zainab) will need to retain your contact information. This information will be kept strictly confidential and anonymous and only me (Zainab) and my supervisors (Diane & Helen) will have access to it.

Copies of your sound-file and transcript will be made available to you if you wish – please just let me (Zainab) know on the day of the interview or contact Diane or Helen within 72 hours of the day of the interview. Their contact details are listed below.

Why have I been chosen?

You have been invited to participate because you have been diagnosed with asthma 12 months prior to this interview, you are a South Asian person over the age of 18 and you either take part in sport or exercise or neither.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

I am interested in taking part, what do I do next?

Please contact me (Zainab) via email or telephone either indicating your interest in taking part or for any further detailed information. Please note that the asking of this information does not place you under any obligation to take part in the study. Please take time to read through the following information carefully and discuss it with friends and relatives if you wish to. Ask me (Zainab) if there is anything that is not clear or if you would like more information and take time to decide whether you wish to take part or not.

What if I agree to take part and then change my mind?

You can withdraw from this study at any time without providing a reason. If you wish to drop out at any stage *during* the course of the interview then please just let me (Zainab) know and any data collected will be destroyed. If you wish to withdraw your interview data *after the* interview you can do this without any

questions and consequences and you will not be asked to explain your reasons. You can withdraw your interview data up to 3 days after you have completed your interview. Should you wish to withdraw your interview data after the day of the interview please contact me (Zainab) (contact details are provided below).

Will my taking part in this study be kept confidential?

The information obtained in the interview will be kept anonymous throughout the study and sound files of the recorded interview will only be kept for 5 years and will then be destroyed. All paper documentation and personal data will be kept securely in a locked filing cabinet to maintain confidentiality. Any linked documents will be stored separately from each other. All paper documentation will be shredded towards the end of 2020 and all electronic data will be stored on password protected computers. Interview data will be anonymised and may be shared within the research team (me and my supervisors). It may be used in the production of papers and articles about the research within that five years after which your data will be destroyed.

You will be asked to pick a pseudonym (a false name) for yourself and any family members or significant others (e.g. friends, colleagues, people you meet etc.) that you mention during the interview. This means that your identity will remain anonymous to everyone except me (Zainab), Diane and Helen. Anonymisation takes place as the data are transcribed (typed up). Any names or places given will also be changed. Nothing will be traceable back to you.

If you do not wish to answer any of the questions that I (Zainab) ask you during the interview, please just say so and I will move on to the next question. If during the interview you say something which you decide subsequently you do not want me to include in the study, then please just say during the interview that you would like that omitted from the transcript. Alternatively we can send you a copy of the transcribed interview either electronically or in hard copy if you so wish and you can edit it yourself. I (Zainab) would require you to return the transcript with any changes within 7 days from receipt please.

What are the possible disadvantages and risks of taking part?

Given the nature of the study, the interview may arouse negative emotions. I (Zainab) will obviously aim to ask questions in a sensitive and compassionate manner and as stated previously you have the right to decline to discuss any aspect that you are asked about. However if you do find participating in the interview a little upsetting at any point you might like to take a break, or if you prefer, you can decide to end your participation and withdraw from the study at that point. Equally, as long as time permits, we can reschedule the interview if you are willing to do so. You will be provided with helpline numbers for further asthma support services, including the Breathe Easy support group, which aim to improve asthma management in the 'Thanks and Debriefing' document that you will be given at the close of the interview.

What will happen to the results of the research study?

Your data will be added to those of several other people who have also kindly agreed to be interviewed for this study. I will then look for common themes in the data and a summary will be produced and fed back to all

participants who wish to receive it. I hope to disseminate the findings to local, national and international conferences and events and in peer-reviewed academic publications. Please note your data will remain anonymous.

I would like to keep parts of your anonymised transcript to use for publication in journals. Please note that participation is **not** contingent on agreeing to this. Your transcript will be destroyed towards the end of 2020 to ensure protection of your confidentiality and your anonymity unless you give me permission to retain a single anonymised copy of your transcript.

What are the possible benefits of taking part?

I hope that you will find taking part in the interview interesting and enjoyable. I will share the key findings with asthma and ethnic minority focused associations if possible and plan to disseminate the findings and publish them in peer reviewed journals if possible. I hope to use the findings to inform and educate health professionals working with people with asthma in the South Asian community by enhancing our understanding of your experiences.

Who has reviewed the study?

This study has been put together following De Montfort University's guidelines for good research practice and has been independently reviewed and approved by the Faculty Research Ethics Committee for the Health and Life Sciences Faculty at De Montfort University. All study materials have been reviewed by experienced ethical reviewers who are fully independent of the study team.

Who is organising and funding the research?

The research will be organised and funded by De Montfort University.

What if something goes wrong? / Who can I complain to?

If you have a complaint regarding anything to do with this study, you can initially approach the lead investigators (Zainab Yusuf, Dr Diane Wensley or Dr Helen Owton whose contact details appear below). If this achieves no satisfactory outcome, you can contact the Faculty Research Ethics Committee, Professor Martin Grootveld, 1.25 Edith Murphy House, Health & Life Sciences, De Montfort University, The Gateway, Leicester, LE1 9BH, 01162 506122, hlsfro@dmu.ac.uk

Contact for further information

Please don't hesitate to contact me (Zainab), Diane or Helen for further information via e-mail, phone or post at:

You can contact me care of my first supervisor:

Zainab Yusuf care of

Dr. Diane Wensley

De Montfort University

Division of Nursing and Midwifery

8.20 Edith Murphy Building

The Gateway

Leicester LE1 9BH

zainab.yusuf@my365.dmu.ac.uk

First supervisor contact details

Dr. Diane Wensley

Email: dwensley@dmu.ac.uk

8.20 Edith Murphy Building

De Montfort University

Division of Nursing and Midwifery

The Gateway

Leicester LE1 9BH

Second supervisor contact details

Dr. Helen Owton *CPsychol*

Email: h.owton@open.ac.uk

Open University

Faculty of Education and Language Studies

Walton Hall

Milton Keynes MK7 6AA

Many thanks for considering participation in my research.

Appendix 4: Consent form (Researcher's copy)

Version 3

07/03/2015

Consent form

Title of project: ***An interview study exploring South Asian people with asthma and their exercise/sporting experiences***

Name of investigator: ***Zainab Yusuf***

Please read the following items carefully and **initial** the box to show that you have read, understood and agree each item.

I can confirm I am over 18 years of age and that I voluntarily agree to participate in a research project conducted and outlined to me by Zainab Yusuf, a PhD researcher studying for a PhD in Health Studies at De Montfort University. ☐

I have been informed withdrawal of interview data may not be possible after 3 days. ☐

I understand I will be able to withdraw during the study at any time without providing a reason. ☐

I can confirm I have read and understood the information sheet (07/03/16 Version 3) for this project and I have had the opportunity to ask questions and have had these answered accordingly. ☐

I understand that I am being asked to participate in an interview (approximately 60 minutes and 15 minutes to read and sign documentation) and respond to a series of questions. ☐

I understand that the whole interview will be audio-recorded and should I wish to stop the recording at any time I may do so by informing the researcher accordingly. The interview will be undertaken in English. ☐

I agree that non-identifiable quotes may be used in published articles or used in conference presentations. ☐

I understand my name and any personal details will be anonymised in any report concerning this study, though I agree that any of the data I provide may be used in the researcher's theses. ☐

I understand I will be fully protected in accordance with the Data Protection Act of 1998, and in compliance with DMU's Health and Life Science's guidelines for good research practice and that my data will be kept confidential and anonymous until it is destroyed. ☐

I give my permission for the researcher (Zainab) to contact me about a potential follow-up interview and retain my details for this purpose. ☐

I give permission for the supervisors to have access to my data. ☐

I agree to take part in this study. ☐

Print name of participant	Date	Signature
_____	_____	_____

Researcher's signature:_____

(*Zainab Yusuf* – De Montfort University)

Email: zainab.yusuf@my365.dmu.ac.uk

Researcher's contact details:

Zainab Yusuf care of

Dr. Diane Wensley

De Montfort University

First supervisor contact details

Dr. Diane Wensley

De Montfort University

Division of Nursing and Midwifery

Division of Nursing and Midwifery

8.20 Edith Murphy Building

The Gateway

Leicester LE1 9BH

8.20 Edith Murphy Building

The Gateway

Leicester LE1 9BH

Email: dwensley@dmu.ac.uk

Second supervisor contact details

Dr. Helen Owton *CPsychol*

Open University

Faculty of Education and Language Studies

Department of Childhood and Youth

Email: h.owton@open.ac.uk

Consent form date of issue: [07/03/2016]

Consent form version number: [3]

Appendix 5: Copy of Ethical approval letter

DE MONTFORT UNIVERSITY LEICESTER

HLS FREC Ref: 1689

4th April 2016

Zainab Yusuf
PhD Candidate

Dear Zainab,

Re: Ethics application – A phenomenological study on asthma and the sporting/exercise experiences of South Asian populations and perceived barriers (ref: 1689)

I am writing regarding your application for ethical approval for a research project titled to the above project. This project has been reviewed in accordance with the Operational Procedures for De Montfort University Faculty of Health and Life Sciences Research Ethics Committee. These procedures are available from the Faculty Research and Commercial Office upon your request.

I am pleased to inform you that ethical approval has been granted by Chair's Action for your application. This will be reported at the next Faculty Research Committee.

Should there be any amendments to the research methods or persons involved with this project you must notify the Chair of the Faculty Research Ethics Committee immediately in writing. Serious or adverse events related to the conduct of the study need to be reported immediately to your Supervisor and the Chair of this Committee.

The Faculty Research Ethics Committee should be notified by e-mail to hlsfro@dmu.ac.uk when your research project has been completed.

Yours sincerely,

Professor Martin Grootveld
Chair
Faculty Research Ethics Committee
Faculty of Health & Life Sciences
De Montfort University

Email: hlsfro@dmu.ac.uk
Web: http://www.dmu.ac.uk/research/ethics-and-governance/faculty-specific-procedures/health-and-life-sciences-ethics-procedures.aspx

Faculty of Health and Life Sciences, Edith Murphy House, The Gateway, Leicester LE1 9BH.
T: (0116) 255 1551 **F:** (0116) 257 7135

Appendix 6: Demographics questionnaire (Researcher's copy)

Demographics questionnaire

Age	
Gender	**M/F**
Self-described ethnicity	
Type of asthma (please circle)	**Intermittent/Mild/Moderate/Severe/Exercise-induced**
Type of prescribed medication	
Type of exercise/ sport (please circle) **Length of participation** (minutes/hours)	**Moderate/Vigorous exercise** **Any sport:** **Length of participation:**

Types of asthma:

Intermittent = symptoms occur either twice a week or less

Mild = Symptoms occur more than twice a week but less than once a day

Moderate = Symptoms occur daily

Severe = Symptoms occur daily and often (for e.g. disrupt sleep)

Exercise-induced = Symptoms triggered by exercise

Types of exercise

Moderate = Raising heartbeat and breaking into a sweat (e.g. speaking whilst exercising but not being able to sing)

Vigorous = Working hard enough so heart rate raises significantly (e.g. not being able to speak much whilst exercising)

References

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NHS (2015) *What is moderate and vigorous exercise?* . [Online] Available from: http://www.nhs.uk/chq/Pages/2419.aspx?CategoryID=52& [Accessed 03/11/2015].

Appendix 7: Example of initial noting on interview transcript

Interview 5: Lubna

Zainab: Okay can you tell me about yourself and your asthma please?

Lubna: Erm okay so I guess like my asthma started from like when I was really young like before I even prob probably even remember like really really young (.) erm it's like always like run through my family but it's more like been like like my asthma was always induced from like allergies more than anything [Lubna sniffs her nose] um so if you like dust allergies so I can't really be around too much dust so it makes me quite wheezy and often like it gets worse in like the summer periods erm and when there's more like pollen and dust and stuff around erm (.) yeah it used to be quite bad when I was little but like it got better as like I grew up coz I used to do quite a lot of erm and when I was growing up I had to do a lot exercise like my parents like encouraged like me to do a lot of exercise then so like cross country and stuff so erm (.) I think that over the years that eventually like I I have the theory that it got better like as I was doing more exercise and I was [Lubna sniffs her nose] I'm always like pushing my body so (.) almost erm I feel like my lungs and everything got a bit stronger [Lubna sniffs her nose] erm and just doing exercise and stuff erm (.) yeah [Lubna laughs]

Zainab: Okay I won't interrupt you when you're talking [yeah that's fine] it makes it easier to transcribe [Zainab and Lubna laugh]

Lubna: No yeah I understand [Lubna laughs]

Zainab: Umm that's interesting so you mentioned it's been passed down

Lubna: Umm not in my mum's family so my dad's family so erm my dad had asthma and my gr I mean my grandma had asthma as well so erm [Lubna sniffs her nose] yeah so I think I got it I think it's genetic erm yeah coz it obviously runs in my dad's side of the family so erm yeah I have it but I do to be fair I do have two younger brothers and they don't have it (.) so erm it's just me but I it probably does have a genetic element to it some yeah somewhere along the line [Lubna smiles] erm [Lubna sniffs her nose] yeah so uhh umm so I think I when my I was little like when I started like showing symptoms of my asthma like my dad kind of knew oh (.) you know like I've got similar symptoms to him erm sort of like wheezing like shortness of breath and things like that so erm went to the doctors got diagnosed for it [Lubna laughs]

Zainab: Okay and you said you ran cross country and you exercise a lot

Lubna: Yeah erm so when I was little like when I first started like doing running and like cross country and I used to swim a lot when I was younger (.) [Lubna sniffs her nose] erm I think like it was really difficult on my body like especially like coz like obviously like being really short of breath like it was quite difficult erm but almost like the more the longer I did it and like the more I sort of spanned it out over like over like over the years like it got a bit easier it got a lot easier in fact (.) but erm I remember specifically at first like I couldn't do anything longer then probably [Lubna sniffs her nose] I couldn't do anything like strenuous on my body I definitely couldn't do anything longer than about half an hour before it got like I started wheezing and I needed

my inhaler [Lubna sniffs her nose] erm [Lubna clears her throat] so yeah but erm I think like that was probably when I was like seven or so and then it got better and like when I was twelve like and there was like this massive difference between like when I was seven and when I was like twelve or thirteen when I was going into like upper school and like [Lubna sniffs her nose] middle school and things like that like I noticed a massive change between [Lubna sniffs her nose] erm how difficult I find sports and I got (.) it also made me feel a lot more confident coz it kind of proved like the fact that I could do sport like and my asthma wouldn't like bring me down as long as I did it at the pace that I want I was comfortable with everything would be okay yeah

Appendix 8: Example of high-level noting

Participant: LUBNA

Topic: EXERCISE AND ASTHMA

Theme: Exercise and asthma	**Extract**	**Exploratory comment [interpretation]**
Line number: 7-10	when I was growing up I had to do a lot exercise like my parents like encouraged like me to do a lot of exercise then so like cross country and stuff	Exercising body – attributes growing out of asthma to growing up exercising – also parental influence to exercise – running in past experience
Line number: 10-13	so erm (.) I think that over the years that eventually like I I have the theory that it got better like as I was doing more exercise and I was [Lubna sniffs her nose] I'm always like pushing my body so (.) almost erm I feel like my lungs and everything got a bit stronger [Lubna sniffs her nose] erm and just doing exercise and stuff	Perception that exercise helped asthma – pushing body = forcing and causing body to become stronger with asthma – pushing body physically and mentally to become stronger
Line number: 28-29	so when I was little like when I first started like doing running and like cross country and I used to swim a lot when I was younger	Running, cross country and swimming (when younger)
Line number: 29-31	[Lubna sniffs her nose] erm I think like it was really difficult on my body like especially like coz like obviously like being really short of breath like it was quite difficult erm	Asthma-body-self interrupted – difficulty engaging in exercise – showing symptoms (unable to conceal)
Line number: 31-32	but almost like the more the longer I did it and like the more I sort of spanned it out over like over like over the years like it got a bit easier it got a lot easier in fact	Fleshy reality of exercising with asthmatic body – bodily consequences – more exercise over years training body to be less disruptive and suffer less bodily consequences – the meaning of exercise important to Lubna (an instrument to make body stronger and challenge asthma)

Line number: 33-35	erm I remember specifically at first like I couldn't do anything longer then probably [Lubna sniffs her nose] I couldn't do anything like strenuous on my body I definitely couldn't do anything longer than about half an hour before it got like I started wheezing and I needed my inhaler	Important – disruption causes exercise to be cut short – limit on exercise potential because of bodily consequences – inhaler used to relieve symptoms (the importance of inhaler at specific times)
Line number: 36-40	probably when I was like seven or so and then it got better and like when I was twelve like and there was like this massive difference between like when I was seven and when I was like twelve or thirteen when I was going into like upper school and like [Lubna sniffs her nose] middle school and things like that like I noticed a massive change between [Lubna sniffs her nose] erm how difficult I find sports	Very descriptive story – remembering a salient moment here where asthma changes (meaning of asthma important to Lubna – accepted as part of identity)
Line number: 40-43	it also made me feel a lot more confident coz it kind of proved like the fact that I could do sport like and my asthma wouldn't like bring me down as long as I did it at the pace that I want I was comfortable with everything would be okay	Reflection on asthma and exercise potential – this salient moment helped her understand her limits and be okay with that – helped that sports were less difficult for her made her feel better that she could do what she wanted to do without asthma affecting her (affects Lubna mentally and physically) her asthma self changed when she went into high school and uses her exercising potential to define her asthma self (others linked to medicine use)

Appendix 9: Example of participant theme table

Lubna, 20-21, Female, moderate asthma, Budesonide/ formoterol 2x a day, Salbutamol as and when required			
No.	**Theme**	**Line no. [Interview 1]**	**Line no. [Interview 2]**
1.	**Understanding asthma** • Responsibility	220-223, 348-352,	284-287, 289-293, 336-344, 349-350, 352-353, 355, 358, 358-361, 366-367, 369, 500-501, 517-518,
2.	**Sporting challenges** • Trying to get fitter • Won't give up • Learning limits • Restricted movement	48-50, 50-52, 216-220, 292-298 224-230 28-35, 39-43, 45-48, 513-523 194-203,	30-37, 39-40, 48-52, 54-57, 64-70, 484-485, 489, 95-102, 12-13, 112, 115, 117, 124-133, 135-136, 196-197, 199,

	• Controlled environment • Achievement	45-48, 298-303, 305-308, 483-496	373-376, 378-381, 383-387, 389-391, 613-614, 619-624,
3.	**Cultural identity** • Connected to western culture • Disconnected • Culture is individual • Woman with asthma	473-480,	303-308, 310-313, 632-636, 638-640, 642, 317-322, 330-332, 655-658, 660-663, 675, 685-688, 693-697 **737-743, 745-747**
4.	**Hcp – patient relationship** • Acceptance • Understanding why	204-207, **338-346** 146-151, 154-158, 160, 266-279, 375-383, 392-397, 397-402,	152-153, 155-157, 163-166, 246-247, 249- 258, 725-727, 420-421, 423-424, 431, 434-436,

5.	**Coping strategies** • Minimising • Support system • Downward comparison	 7-11, 101-104, 107-112, 115-122, 126-129, 291, 332-338, 97-99, 170-174, 191-194,	 205, 207, 209, 361-362, 592-594, 597-598 277-278, 295-297,
6.	**Working with the weather** • Seasonal	 53-56, 60-69, 232-234, 234-241, 241-244,	 225-230,
7.	**Public display of asthma** • Understated • Stigmatisation	 105-107 133-142, 310-328, 359-371,	 271-275, 397-400, 402, 404-407, 463-464, 467-468, 470, 472-473,
8.	**Emotional states** • Self-blame (panic) • Resentment	 91-94, 420-425 142-146, 310-328,	 537-539, 541-542, 547-548, 550-552, 560-564, 566-568, 570-572, 574, 578-579, 581-583,

Appendix 10: Clustering of themes

Disruptive life	**The re-covery process (re-presenting the sporting self – self-body association)**	**"You've gotta play your role in this" – Taking responsibility**	**Medical culture**	**Stigma** **Feeling judged by others**	**Supportive networks – reassurance**

Knowing about triggers – loss of control 'It's not a nice feeling' (sudden, unexpected, uncontrollable) Being extra wary (paying attention) Fear of unpredictability of asthma – reminder(s) Resistance to hospitalisation (quick fix) dependence on inhaler (annoying annoyance – Jamal) **"Teach yourself" - learned responses (avoidance tactics) – mind-body associations (breathing**	Being comfortable – **finding the right balance** (regulated stress on body) – includes taking inhalers when aware body can't cope – learning experience – successful adaptation – taking inhalers beforehand to push (Jamal/ Nafisa/ Kalan) **"Keep going" - Improving sporting mind body self** (Aisha/ Lubna/ Jamal/ Kalan/ Reena (wellbeing & Dhaya) – Accomplishments in sports and exercise – feeling inadequate? – overcoming asthma? (Lubna/ Jamal)	Conceptualisations of exercise and health – too lazy/ irresponsible - Current trends in SA culture – fluidity of cultural identity? – what culture means?	Resistance to medication (side effects (Aisha/ Nafisa), over medicalised (Reena/ Faheema/ Nafisa/ Dhaya?/ Priti) difficult to accept different culture? (Priti) (distancing dependency) **Searching for alternative treatments** – treatment accepted when necessary - Religious context – superstitious beliefs? Blame culture – pressure on patients - fear	**They don't understand" – treatment stigmatised (concealment) – family life/ marriage worries** **Chronic illness stigmatised** **"Girls aren't always encouraged to do intense exercise" – the role of gender and culture? –** redefine women's cultural identity Treatment during fasting **Hypervigilance – avoidance tactics (Presentation of self)** **"Oh that's ridiculous, you can breathe" – educating**	**Parent's role (asthma is shared with significant others)** **Feeling guilty** Seeking advice – link to Kalan (lack of taking advice on board?) "You're not alone" – advice for others with asthma

patterns) – knowing the body? Continuous struggles – stress related disruptions, "Always getting ill", loss of old self **Techniques - Minimising condition** - "Learn to live with it" Normalising condition (cognitive strategy) – Comparisons to others Feeling lucky- Distancing (cognitive strategy – role distancing (Goffman) - Feeling okay	Fighting asthma - Avoidance (tactics – behavioural strategy)- Resistance to medication - Denial behaviour - questioning ill self (contingent) (mind body self-relations - Younger – fighting disruption in sports (Reena/ Tasneem/ Nafisa/ Jamal) **Working with the weather** - "Air that's messed up" – polluted air - Avoidance tactics- Concurrent illness (hayfever – link to sports and exercise)		**'They're not gonna do anything'** – hcp role "5 minute slot" – Wanting care? – Education awareness about preventer (I don't know what it does) **Faith in medical practitioners**- accept treatment (Jamal/ Kalan/ Nafisa/ Priti)	**others about the severity of asthma** Control over disclosure?	

resistance to medications **“It stopped me from exercising” – Taking away the sporting self** (Reena/ Tasneem/ Lubna/ Aisha) – ‘ illness doesn’t define my sporting identity’ – resilience – threatens sporting self (Enayah, Tasneem, Lubna, Indiana)					

Appendix 11: Superordinate themes using abstraction

Managing sport and exercise	**Cultural stigma**	**'Other South Asians are lazy': Challenging cultural standards**	**Managing medication**	**Negotiating the asthmatic identity**	**Relationships with healthcare professionals**	**Searching for non-pharmacological treatments**
Finding the right balance	Misperceptions about asthma				Engaging in a therapeutic relationship	
Feeling self-conscious	Challenging cultural and Gender Identities				Unmet expectations of care	

Appendix 12: Extract from reflexive diary (events & recruitment)

Entry 1 (16/06/2016)

I visited an event today to try and recruit some participants. It was held at the Shree Prajapati Association Temple in Leicester. It began at 7pm and lasted until 9pm which was quite long and overran quite a bit finishing at 9.30pm. It was the South Asian Diabetes Event so I figured a lot of people would turn up, about 35 people turned up but unfortunately none of them had asthma. One person did pick up a leaflet and mention his daughter had asthma but unfortunately no one has yet contacted me. As it was Ramadhan, I couldn't stay longer than 9.30pm I had to get home pretty quickly which meant I could not stay after the event had finished to hand out my leaflets and speak about my study. Instead I handed my leaflets out to a fellow PhD colleague I knew and she handed them out for me but alas no one has contacted. I did manage to network and caught the attention of the manager of [*name retracted for confidentiality reasons] and will contact him in due time.

Appendix 13: Extracts from reflexive diary (interviews)

Entry 1 (24/06/2016) Interview: Reena and Nafisa

I had my first two interviews today with Reena and Nafisa. I had contacted them beforehand via telephone and Facebook and managed to interview them as soon as possible. They were both lovely and very talkative about their asthma and experiences. I didn't really have to speak much to be honest, they were both very frank and open in discussion which helped because I hadn't piloted my interview guide. Now that I have used it, I feel more confident in my approach and don't feel the need to adapt it. The interviews were both treated as a conversation. I wanted it to feel like a conversation because I feel it makes the participants feel more at ease and helps them open up that little bit more. Nafisa was rushing slightly at the beginning of the interview (we were running late and she had to go pick up her kids from school) so I felt a little uneasy about how to judge the situation. Luckily, she eased in to it after a while and started speaking at a slower pace. She didn't seem worried much about the timing after that but we ended up finishing on time give or take a few minutes. Reena was my first interview and I had treated her interview as a mini pilot, it ran over slightly (about 15 minutes) but I ended up with a lot of data.

I feel much more confident going into my other interviews and I know with this topic guide I can get at least an hour's (minimum) worth of data from each participant. Let's see if I can get book a few more people before my summer break. I hope I can but people don't seem to be responding as well as I'd hoped. I think people are a little wary of speaking about their asthma it's still seen as an illness people are unwilling to discuss or accept which is a shame.

Entry 2 (22/09/2016) Interview: Aisha

Today I visited Aisha, a very friendly woman who kindly participated in the interview. The interview was at 5pm, I mention this because I was quite tired and Aisha had forgotten about the interview so I waited another 20 minutes for her to arrive. It was a fairly good interview, I felt as though Aisha wanted to talk more about her job and was treating me like a counsellor rather than speak about her asthma. I did have to slightly nudge the conversation so that she would refer back to her asthma instead. The interview was also interrupted; Aisha's two daughters came into the room to speak to her whilst we were speaking. That said, it wasn't a major interruption but after Aisha's daughters came back from their outing I think Aisha felt as though the interview was over and it was time to prepare dinner. It was getting to 6pm. It's a slight problem scheduling the interview for 5pm or later because there's other tasks to do, such as cook dinner or even just rest and relax. Working all day is tiring and by having the interview at 5pm, I was quite tired and wasn't able to concentrate as much as I would have liked which I think affected the way the interview went.

Aisha was really friendly after the interview even offering me dinner. I think from this interview I will consider conducting interviews in the morning or afternoon time. Aisha's interview was at home whereas my previous interviews were conducted at DMU. I felt the interviews conducted at DMU were much easier and I felt much more comfortable whereas home interviews tend to make me less comfortable.

Entry 5 (30/11/16) Interview: Lubna

Today I interviewed Lubna in the morning. It was, I think a really good interview. She spoke very openly about her experiences of asthma and exercise. She runs 5 days a week which was really crucial to the interview. I tried to gather as much experiential information as I could about her exercising and asthma. It seems as though exercise didn't seem to disturb her asthma but was more of a gesture to her asthma that she could succeed at something that limited her in her childhood. I found an emotional representation to asthma with Lubna. She seemed emotionally connected to her asthma and mentioned it was really difficult to explain or describe her asthma to others, especially when someone asks her whilst she's experiencing symptoms what she's actually feeling at that moment. She mentioned that asthma was a very personal thing quite warm heartedly at the end of the interview again emotionally connecting her to her asthma. There were quite a few identity issues in Lubna's interview. She mentioned quite a lot how her asthma lowered her self-confidence and her self-esteem and how her identity from accepting her asthma made her stronger in the long run. This interview would be perfect to incorporate into my findings from my undergrad. study and I hope to do that later. I think we also happened upon the idea that 'asthma is a concept', it's so difficult to explain and describe and it happens without you actually being consciously aware of what's happening in your mind so that's something I will look to explore further.

I didn't tell Lubna I suffered from asthma and acted as an outsider because I wanted to see if she would describe her experiences more to someone she thought would not understand. I think it worked, I didn't want her to be influenced in any way by me being a sufferer but I think it created a gap too where she felt comfortable talking about it but felt uncomfortable speaking to someone who may not know what she's feeling (yet I did luckily). So I'm not sure which approach to choose next time. I have been telling all previous participants that I have asthma and that kind of creates a very open understanding dialogue…I'm not sure if it did this time around. I think it did but I'm not sure which approach is better. I think I feel more comfortable telling them I have asthma so that they feel like someone understands. What I get from most of these interviews is that they are always looking for someone to understand how it feels to have asthma and by telling them I do it helps them speak openly but I know me agreeing to certain experiences may influence them or may influence them to speak about something they think I want to know about because I experienced it too.